

MENTAL HEALTH EFFECTS ON THE FAMILY  
WITH CHRONIC ILLNESS

A THESIS-PROJECT  
SUBMITTED TO THE FACULTY OF  
GORDON-CONWELL THEOLOGICAL SEMINARY

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE  
DOCTOR OF MINISTRY

BY  
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MAY 2017



To my loving spouse, Michele, who, through myriad circumstances and devastations has never left my side in this journey. Her dedication and love has been insurmountable, and her support for this project, undefinable. Her own success and journey has been nothing short of miraculous.

To my daughter, Jennie and son Jacob, examples of perseverance, tenacity and fight. You two have proven in life the reality of never ever giving up. Your personal successes have been inspiring and motivational.

Thank you!

The music is all around us, all you have to do, is listen...

-Freddy Highmore, *August Rush* (2007)

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## ABBREVIATIONS

AAMFT	American Association Marriage Family Therapy
ADHD	Attention Deficit Hyperactive Disorder
EFCT	Emotion Focusing Couple Therapy
EFFT	Emotion Focused Family Therapy
EFT	Emotion Focused Therapy
MS	Multiple Sclerosis
NMSS	National Multiple Sclerosis Society
NASB	New American Standard Bible
OCD	Obsessive Compulsive Disorder
PMDD	Pre-menstrual dysphoric disorder
PTSD	Post-traumatic Stress Disorder

## ABSTRACT

As a therapist, I face no greater challenge in my work than the mental health of a client, and the consequent effects of clients personally, and the ramifications for family and friends of those close with the client. The methodology of research was multi-fold from the identified family that served as a platform for observation to learn, observe, and to evaluate. With the vast availability of bibliographic material available, parameters were set to focus clearly on the topic what are the mental and emotional effects on the family experiencing a loved one, with long term illness.



## **CHAPTER ONE**

### **THE PROBLEM AND THE SETTING**

#### **Dealing with the Family of a Loved One with Long Term Illness**

As a therapist, I face no greater challenge in my work than the mental health of a client, and the consequent effects of clients personally, and the ramifications for family and friends of those close with the client. Brain and Behavior Foundation (2017) presented facts of those disabled in the U.S. and reported that about 25 percent of adult Americans suffer from brain and behavior disorders. Diagnosis of these illnesses are identified earlier than in the past as 20 percent of children have been shown to live with mental illness. Brain and behavior disorders, including major depression, bipolar disorder, schizophrenia and obsessive compulsive-disorder make up four of the 10 leading causes (Brain & Behavior, 2017, para.1).

In 2006, following months of medical interventions, I entered the world of mental illness in a new position I never thought I would encounter. As a Type-A, or high energy and competitive personality, I came up against the fact that the world of perfect fixes, high success, and problems with quick and easy resolve, would lead into days of chaos and confusion.

According to current and relevant research, it is estimated that 18 percent of adults are affected by an anxiety disorder such as Post Traumatic Stress Disorder, Obsessive Compulsion Disorder, and specific phobias each year, and 7 percent of adults will experience severe depression. Attention-deficit hyperactivity disorder affects 4

percent of adults and 9 percent of children each year. Additionally, 3 percent of adults live with schizophrenia and 3 percent live with bipolar disorder (Brain and Behavior, 2017, para. 3).

Dante wrote, “In the middle of the journey of our lives, I found myself upon a dark path” (Real, 1997, p. 21). The passion of this therapist, brought on by his own journey and the effects on his family is the catalyst to undertake this research to touch the lives of many like him, in similar circumstances. Depression, when directly attributed to long term health conditions, has profound effects on a patient and the family and loved ones surrounding him or her. While depression is but one of many mental health conditions affecting individuals in the United States, this project examined depression, resulting from physical health challenges and the impact on the home. Multiple Sclerosis, Cancer, Alzheimer’s, chronic back pain, are but a few of the examples of those challenges.

To fully understand the scope of this project, it is important to lay out the demographics and importance of dealing with the mentally ill, specifically suffering from depression, when directly affected by long term disease. Over the past 3-5 years, this therapist encountered a male client and his family who were facing a diagnosis with long term illness, Multiple Sclerosis (MS). They suffered daily with the psychological diagnosis of Major Depressive Disorder (MDD). This father of three, married 18-20 years struggled daily with the impact of this diagnosis. It would be a blatant error in treatment to overlook the compound effects of long-term illness on the family. This family experienced the empirical, psychological, emotional, and spiritual effects of this

devastating disease. In the pages, ahead, this researcher sought to answer the question, what are the mental and emotional effects on the family experiencing a loved one with long term illness? This project looked through the eyes of this family and the experience of multiple sclerosis as it affected the father and husband. His life essentially came to a standstill, because of no medical and mental health answers for his dilemma. The need for education and understanding of his dilemma was paramount to not only him, but also his family.

While there were multiple long-term illnesses that could be examined in this study, the diagnosis of remitting and relapsing MS will serve simply as an example of the hundreds of diseases that plague society and their families today. There is something about multiple sclerosis MS that disrupts families at every level: "I've often talked about it as the uninvited guest," said Rosalind Kalb, vice president for health care information and resources at the National Multiple Sclerosis Society. Esposito (US News and World Report, 2015) aptly stated, "This disease shows up in your household, moves in, spreads its junk all over and doesn't leave. It means everyone has to develop a relationship with this intruder" (para. 2).

The expectations of this project were, that at the end of the day, the countless millions of those suffering with resultant depression, either personally or as family member, would have a set of emotional and mental health tools to embrace their reality. The hope for those reading this project or experiencing the resultant workshop was that the message that this "intruder of the soul" (Esposito, 2015, para. 3) would no

longer be hidden and help and hope was available beyond the confines of the walls they created to keep the beast at bay.

In the pages, ahead, assumptions were made based upon research and personal experience that mental disease, specifically depression, was many times misunderstood and mistreated. It was often overlooked, and an unwelcome guest in the world of the church. Dwight L. Carlson wrote:

The widespread nature of Christianity's prejudice can be seen in churches across the nation on any Sunday morning. In most of our churches we pray publicly for our parishioners with cancers, a heart attack, or pneumonia. But rarely will a conservative church publicly pray for Mary with severe depression, Charles with incapacitating panic attacks, or the minister's son with schizophrenia. Such a conspiracy of silence for Christians to have. And by our silence we further wound them in pain. (Carlson, 1994, p. 17)

The methodology of research was multi-fold: First and foremost, the family was observed as a case study to better understand MS and depression's impact on the family. Secondly, review and research of current literature and theology, pertaining to depression, in the confines of long term illness was made. With the vast availability of bibliographic material available, parameters were set to focus clearly on the topic what are the mental and emotional effects on the family experiencing a loved one with chronic illness? To complete this research, it was important to understand the depth and impact of both multiple sclerosis and major depressive disorder on our society.

## **Multiple Sclerosis.**

The National Multiple Sclerosis Society (2016) stated MS affected people between the ages of 20 and 50 years of age, over 2.3 million worldwide, and MS occurred in young children and significantly older adults. MS is not race specific, although it is commonly found in White people of northern European ancestry. In addition, MS is at least two to three times more common in women than men (NMSS, 2016, para. 1-3).

While the jury is still out throughout empirical research (Shadday, 2007, p. 68-69), genetics can have a significant role in determining who develops MS. The average person in the United States has a .002 percent (1 in 750) chance of developing MS. Important to this project was the reality that first-degree relatives of a person with MS, such as children, siblings, or non-identical twins, faced the knowledge that the risk of them being afflicted with MS rose to approximately 2.5-5 percent. In addition, MS was found in an identical twin, the other twin had a 25 percent chance of developing the disease (NMSS, 2017, para. 1-3).

***Types of MS.*** The medical community identified and attempted to categorize the different types of MS. Allison Shadday (2007) listed four of the common diagnoses:

1. Relapsing remitting MS (20-30%), periods of relapse followed by full or partial remission.
2. Secondary-progressive MS (50% of patients with Relapsing Remitting MS, 10-20 years following diagnosis), slow increase in disability without remission.

3. Primary-progressive MS (12%), slow but steady increase in disability from onset of diagnosis.
4. Chronic-progressive MS (10-20%), slow worsening of symptoms, without periods of remission, but the onset is much slower than Primary-Progressive MS. (Shadday, 2007, p. 12)

The effects of being diagnosed with MS were multifaceted. They ranged from relief to denial, from anger to the continual question of “why me?”. Miller (2017), a spokeswoman for the National MS Society on mental health, described several effects of the MS diagnosis. In the beginning, patients were in denial, anger, and in some cases relief that they did not have a disease with a death sentence. Stages of grief were present as patients asked, “why me?” and attributed the disease to punishment. Patients struggled with self-esteem and attempted to cope with a change in identity and status of their role. A preference to remain in the home - sometimes due to the unexpected flare-ups of the disease and keep the disease hidden prevailed, though family members urged the patient to get out of the house and into support networks. MS became a large part of the family and all experienced the effects of the disease. The patient continued to struggle with acceptance of the disease (Miller, 1998, pp. 4-10).

Dr. Miller is a leading authority and author, on the effects of MS on the client and the family, and worked alongside the National MS Society in aiding families of MS. Her book, *Fatigue and Multiple Sclerosis: Evidence Based Management*, is highly recognized within the MS world.

## Depression

Naomi Judd (2016) described the terrifying descent into the depression that intruded and captivated her life. Hers is a story of pain and ultimate hope.

It's three in the morning and I go from a deep sleep to standing bolt upright on my bed, the covers draped around my feet like the statue of liberty, but I am not free. I am imprisoned in my body; my mind has taken me hostage in ways that are unbelievably terrifying. I reach up to my throat expecting to find a pair of hands belonging to an intruder who is out to kill me with a grip that is slowly, closing down, on my windpipe. I am hyperventilating...my vision blurred, the room spins, my face, neck, chest and palms are covered with sweat. (Judd, 2016, p. 14)

Depression can visit its patient in various diagnoses. In the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.) or DSM-5, (American Psychiatric Association, 2013), listed nine of these diagnoses. Seven of those are listed below:

1. Major Depressive Disorder defined as an individual experiencing at least five or more symptoms of depression for a period of two weeks or longer.  
  
Examples of symptoms include: Depressed mood or irritability, decreased interest or pleasure, significant weight change, change in sleep, change in activity, fatigue or loss of energy, guilt/worthlessness, decreased concentration and heightened suicidality.
2. Persistent Depressive Disorder or Dysthymia defined as persistent effects of depression, low grade, for two years or longer.

3. Bi-Polar Depression or Manic-depression persistent ups and downs of depressive and manic emotions for a period of two weeks or more.
4. Seasonal Affect Disorder a season of major depressive disorder usually related to weather, climate, and darkness.
5. Psychotic Depressive Disorder Major Depressive Disorder with attachment to psychotic events, i.e. delusional, hallucinogenic events.
6. Premenstrual Dysphoric Disorder (PMDD), usually associated with monthly periods or premenstrual cycle. It is experienced primarily during the cycle itself.
7. Atypical Depression represents symptomology of depression but can be treated by changing event or circumstances. Can also serve as a precursor to any of the diagnosis listed above.

“During their lifetime 50% of all people with multiple sclerosis (MS) will experience depression in some form” (Shadday, 2007, p. 68). “It (depression) is a soul-smothering, hope-destroyer, fearful...” (Rest Ministries, 2014, para. 3). Depression is one of the most undertreated diseases especially within the community of those with MS. It is often unrecognized by the client with MS and within the medical community. Depression, when associated with MS, was life threatening. Suicide resulting from depression was the third leading cause of death among MS patients (Shadday, 2007, p. 68).

***Underrecognized.*** According to the National Institute of Mental Health (NIMH, 2016), depression affected over 19 million Americans every year. Additionally, the Surgeon General report of 1999 reports:



The current prevalence estimate is that about 20 percent of the U.S. population are affected by mental disorders during a given year. The surveys estimate that during a 1 -year period, .22 to 23 percent of the U.S. adult population-or 44 million people -have diagnosable mental disorders. In general, 19 percent of the adult U.S. population have a mental disorder alone (in 1 year); 3 percent have both mental and addictive disorders; and 6 percent have addictive disorders alone.<sup>3</sup> Consequently, about 28 to 30 percent of the population have either a mental or addictive disorder. (OSG (1999), Regier et al., 1993b; Kessler et al., 1994, pp. 45-48)

Older adults make up 12 percent of the US population, but account for 18% of all suicide deaths. (2016) This is an alarming statistic, as the elderly are the fastest growing segment of the population, making the issue of later-life suicide a major public health priority. Not counted are "silent suicides", like deaths from overdoses, self-starvation or dehydration, and accidents (AAMFT, 2016, para. 1). The Center for Disease Control (2016) reports:

Suicide is increasing against the backdrop of generally declining mortality, and is currently one of the 10 leading causes of death overall and within each age group 10–64(4). This report highlights increases in suicide mortality from 1999 through 2014 and shows that while the rate increased almost steadily over the period, the average annual percent increase was greater for the second half of this period (2006–2014) than for the first half (1999–2006). Increases in suicide rates occurred for both males and females in all but the oldest age group (75 and

over). Percent increases in rates were greatest for females aged 10–14 and for males, those aged 45–64. (CDC, 2016, para. 1)

***Undertreated.*** “Depression is a common, comorbid condition with multiple sclerosis (MS). Historically, however, it has been undertreated” (Raissi, 2015, p. 293). Additionally, of over 165 MS patients interviewed in Raissi’s study, over 66 percent reported they were given no medications for the depression they suffered. The National MS Society reported, “Depression is a major risk factor for suicide. The primary reason why the risk of suicide, among people with MS is unacceptably high is undiagnosed and under-treated depression” (NMMS, 2016, Connection). Factors such as the unpredictability of the disease, major life changes, loss of mobility, and interference with work were leading causes of depression among MS patients. Additionally, multiple MS support agencies reported depression remained high on the list of undertreated comorbidity factors among the MS community (NMSS, 2017, para. 3).

***Overlooked in Communities of Faith.*** Depression was once looked at with shame and stigma and something not talked about. “Shame and stigma can keep people from sharing their experience with those who know them, even those who are closest to them... Mental illness is the sort of thing we don't like to talk about. It doesn't reduce nicely to simple solutions and happy outcomes. So instead, too often we reduce people who are mentally ill to caricatures and ghosts, and simply pretend they don't exist” (Simpson, 2013, pp. 4-7). “There’s an assumption among many people that if they were honest about what they experienced, it would be rejected or they would be shamed” (Cutrer, 2015, para. 4).

## **Multi-Tiered Approach**

Caring for the mental health of those suffering from MS, and the resultant depression, challenges the therapeutic world. Suicide, unemployment, sociologic impact, and the impact on family of depression all represented many of the side effects of depression among those with chronic illness. This intersectionality of MS and depression challenges the therapist to see past the mental health issues to the preponderance of physical and social symptomology.

In a study (Bambara, J; Turner, A; Williams, R; Haselkorn, J, 2014, pp. 230-235) among caregivers of multiple sclerosis, the social support and depressive symptoms included areas such as work, finances, housing, social life, marriage, and family. It was stated that as the disease (MS) symptoms increased, so did the physical and social. The levels of stress associated with each of these symptoms are only exacerbated with the heightening of the disease.

What steps can be taken to ensure a successful outcome in one's client? This therapist was convinced it took a multi-tiered approach. A collaboration with the medical community, and the parallel use of two psychological, individual, and family approaches or systems proved to elevate the probability of success in the MS and Depression client.

This therapist had numerous approaches he used to meet the need of the family and marriage. As a therapist, I could not avoid the tenets of faith in my character and presence with my clients. While I did not make my faith the agenda of therapy, it certainly defined the passion I had for people and the hope within the tools I utilized to

bring success and peace to dysfunction, calm during proverbial storms, and empathy when no one else would feel. It is through use of prayer and meditation, Christian literature including the Bible, and an empathetic and passionate listening ear that my faith is brought into the therapy room.

Over my years of providing care, of not only pastoral centered counseling but marriage and family therapy, I came to a position of integration through basically two tenants of therapy: I am primarily a Narrative Therapist (White & Epston, 1990) and believe the story is of utmost importance. Secondly, I relied upon Emotion Focused Therapy (Johnson, 2007) as the foundation of my listening and resonating ear, with emphasis on Attachment Theory (Bowlby, 1971) The following sections will define these methods of therapy.

**Narrative Therapy.** Michael White and David Epston (White & Epston, 1990) collaborated on this approach to therapy early in the 1970's, revolutionizing the field of family therapy. Their work emphasized the separation of client from their problem-saturated story into more of an open space to reconstruct a new and more encouraging view of themselves (Nichols, 2013). Nichols went on to state that this approach to therapy, "transforms identities from flawed to preferred, not by getting family members to confront their conflicts but separating persons from problems and then uniting the family to fight the common enemy" (Nichols, 2013, pp. 273-274).

Narrative therapy seeks to deconstruct, then reconstruct using questioning assumptions. The approach is centered on three stages: recasting the problem as an affliction (externalizing), finding exceptions, or partial triumphs over the problem and

instances of effective actions, and recruiting support. (Nichols, 2013, p.284) Nichols identified six elaborate series of questions that Narrative therapists used to arrive at their goals with their clients:

1. Deconstruction questions: To externalize the problem. Example: When does anger whisper in your ear?
2. Opening space questions: To discover unique outcomes. Example: Has there ever been a time when arguing could have taken control of your relationship but it didn't?
3. Preference questions: Assure unique outcomes represent preferred experience. Example: Was this way of handling things better or worse?
4. Story development questions: To develop a new story from the seeds of (preferred) unique outcomes. Example: How is this different from what you would have done before?
5. Meaning questions: To challenge negative images of self and emphasize positive agency. Example: What does it say about you that you were able to do that?
6. Questions to extend the story into the future: To support changes and reinforce positive developments. Example: What do you predict for the coming year? (Nichols, 2013, pp.284)

The goal of Narrative therapy is simply, as Nichols (2013) stated, "freeing people from oppressive cultural assumptions and empowering them to become active authors of their own lives" (p. 273). Using personal narrative and social construction, with

personal metaphors the narrative self begins to emerge. It answers the question of who is in charge, the client or the problem (p. 275). Perhaps the strength of this approach lies in the third stage, recruiting support, or building audiences of support for the client. This stage reminds this therapist of the effect of community on the spiritual formation of an individual. The input, passion, teaching, listening, and caring development of others into the spiritual life of an individual serves to round out and authenticate the person's personal spiritual journey.

**Emotion Focused Therapy.** "Emotion is the music of the couple's dance and so organizes key interaction" (Johnson, 2004, p. 14). She summarized the use of emotion focused therapy (Johnson, pp.23-25). Emotionally Focused Couple Therapy (EFT) was created through a collaboration of two therapists, Johnson and Greenberg (Greenberg & Johnson, 1986, Johnson & Greenberg, 1985). Together, they sought to address the absence of clear procedures and protocols that were validated and worked within couple therapy. EFT grew into existence as a direct result of drawing attention to the "crucial significance of emotion and emotional communication in the organization of patterns of interaction and key defining experiences in close relationships" (Greenberg & Johnson, 1986, p.14-16).

EFT is integrative; it looks within and between. It integrates an intrapsychic focus on how individuals process their experience, particularly their key attachment-oriented emotional responses, with an interpersonal focus on how partners organize their interactions into patterns and cycles. It considers how systemic pattern, inner experience, and sense of self evoke and create each other (Johnson, 2004, p.14-16). EFT

seeks to move a couple and or person away from negativity/rigidity to flexibility and sensitivity. The results are security as well as intimacy. EFT expands experience and interaction with goals to access and reprocess the narrow and rigid self. EFT creates a new interactional event thus redefining relationship. When it works, and clients and therapist gel in relationship, the clients become a source of their own security, and contact-comfort for each other, i.e. they assist one another in their journey (Johnson, 2004, pp. 16-18).

In EFT, the therapist serves much like a choreographer, a process consultant, or reconstructionist in the journey. The focus of EFT is always the here and now. History is only focused on when it is being played out in the present. It is a dance between therapist and clients. (Johnson, 2004) EFT comes directly out of the experiential world, reflected Carl Rogers (1951) and the structural systems therapy, authored by Minuchin (Minuchin & Fishman, 2004). It is experiential in that it focuses on how people actively process and construct their experience. The power of the therapist's empathy and validations is important, believing in the great capacity that human beings have within themselves, for growth. The inner and outer realities define one another, in that emotions communicate in others in a way that pulls emotional responses that are key to relationship definition and in that it fosters and heightens a new corrective emotional experience in the here and now. EFT is systemic in that it focuses on context, structure, process of interaction, rigid negative interactional cycles and circularity (Johnson, 2004, pp.18-20).

EFT seeks to de-escalate negative cycles of interaction by creating alliance and delineating conflict, by identifying the negative interactional cycle, by accessing unacknowledged emotions and reframing the problem in differing terms of presentation. EFT seeks to consolidate and integrate with new solutions to old relationship problems and new positions and new cycles of attachment behaviors (Johnson, 2004, p.18). It is essential that EFT and attachment theory be interwoven in approach to therapy.

**Attachment Theory and EFT.** What is attachment how does it relate to EFT?

[Attachment is] a biological instinct in which proximity to an attachment figure is sought when a child senses or perceives threat or discomfort. Attachment behavior anticipates a response by the attachment figure which will remove threat or discomfort (Bowlby, 1960).

Attachment (Bowlby, 1988) is divided into four main types: Secure attachment, anxious-ambivalent attachment, anxious-avoidant attachment and disorganized attachment. In secure attachment, the individual can rely upon their caregiver to attend to the needs of proximity, emotional support and protection. In Anxious-ambivalent attachment the individual feel separation anxiety, not assured even when the care provider has left. In the anxious-avoidant the individual feels complete avoidance by their care provider or parent and in disorganized the individual feels a complete lack of attachment (Bowlby, 1988, pp. 273-275).

Attachment theory when applied to adult relationships is a “revolutionary event for couple therapy” (Johnson, 2007, p. 23). Sue Johnson states that it provides the



couple therapist a coherent, relevant, well-researched framework for understanding and intervening in adult love (Johnson, 2007, p. 24). With the appropriate intersection with EFT, the framework can and does change the landscape in effective couple and family therapy. In her book, *The Practice of Emotionally Focused Couple Therapy: Creating Connection*, Johnson (2007) lists the ten central tenets of attachment theory and serves as a foundational piece of this therapist's approach to working with couples:

1. *Attachment is an innate motivating force.* It is a core defining feature in close relationships and "the heart of the matter". Fear of isolation and loss is found in every human heart.
2. *Secure dependence compliments autonomy.* In Attachment Theory, there is no such thing as independence from others or overdependence. Secure dependence fosters autonomy and self-confidence. They are two sides of the same coin. "...more coherent, articulated and positive sense of self" (Mikulincer, 1985). The more securely connected we are, the more separate and different we can be.
3. Attachment offers an essential safe-haven. "Proximity to a loved one tranquilizes the nervous system" (Schlore, 1994). Attachment is the natural antidote to inevitable anxieties and vulnerabilities of life (p. 26).
4. Attachment offers a secure base. Offers a base to explore and respond to environment, encourages exploration and a cognitive openness to new information, continually updates models of self and others, strengthens the ability to stand back and reflect on oneself, one's behavior, and one's mental

states, and individuals are better able to reach out and provide support to others and deal with stress and conflict positively.

5. Emotional accessibility and responsiveness builds bonds. Emotion activates and organizes attachment behavior. When accessibility and responsiveness work together, they provide the building blocks of secure bonds. “Emotions tell us and communicate to others what our motivations and needs are: they are the music of the attachment dance” (Johnson, 1996).
6. Fear and uncertainty activate attachment needs. When fear, crisis, trauma rise... attachment behavior, such as proximity seeking, are then activated.
7. The process of separation distress is predictable. Bowlby (anger) viewed anger, for example, as “often being an attempt to make contact with an inaccessible attachment figure and distinguished between the anger of hope and the anger of despair, which becomes desperate and coercive” (as quoted, p. 27).
8. A finite number of insecure forms of engagement can be identified. Research support the idea that there are limited responses the individual can make in lieu of unresponsiveness of attachment. Anxiety and avoidance stands out in literature (Fraley and Waller, 1998) When connectedness is threatened but not yet severed three responses are prevalent: Hyperactivated and overdrive, anxious clinging, pursuit, attempts to control and escalation. Deactivation of attachment needs and system, anxious preoccupied clinging and detached avoidance and a combination of seeking closeness and then

fearful avoidance of closeness when it is offered or “fearful avoidant” behavior (Bartholomew and Horowitz, 1991).

9. Attachment involves working models of self and other. Definition of self in context of our most intimate relationships.
10. Isolation and loss are inherently traumatizing. Attachment is a theory of trauma essentially. (Johnson, 2007, pp.25-32)

In summary, EFT redefines the principle of therapy from an old model to a new. Illustrated, the old model would be the client and the therapist on opposite ends of a tennis court, with the net provided “professional” and safe distance in therapy. EFT removes the net and places the therapist and his clients on the same side, dealing with the now removed issue or symptom. Together, in relationship and mutuality, they discover and allow for discourse.

### **Summary**

Multiple Sclerosis and its accompanying mental health challenge of depression serves as the primary challenge of this project. Approaching this topic through the academic eyes of both EFT/Attachment Theory and Narrative Therapy is center to the success of this venture. MS and its accompanying depression has been briefly defined and understood, however, it would be a failure not to fully understand the place of the family in this life changing crisis. It is imperative to the family case examined in this project that a full understanding of family from a Biblical viewpoint be examined in chapter two.

## **CHAPTER TWO**

### **FOUNDATION OF FAMILY**

Society has undergone significant changes since the days of Ozzie and Harriett in the early sixties. The days of the nuclear family, mom and dad, brother and sister, and the dog are all but gone. Statistically, Lisa Belkin (2011) states, it is no longer a mother, father and their biological children living together under one roof (and certainly not with Dad going off to work and Mom staying home). Although perception and acceptance often lag reality, there is evidence that a new definition of family — while far from universally accepted — is emerging (Belkin, 2011, para. 1-2).

Lisa Belkin wrote about a randomized study (Pew Research Center, 2011) of over 2,671 people attempting to define “family” conducted with compelling results:

More unmarried couples raising children; more gay and lesbian couples raising children; more single women having children without a male partner to help raise them; more people living together without getting married; more mothers of young children working outside the home; more people of different races marrying each other; and more women not ever having children. (Pew Research Center, Belkin. Para. 3)

Seven distinctly, different definitions from the norm do exist. The family has changed, ABC News reported in 2010. A changing definition of family was defined, by Berman and Francisi (ABC News, 2010). "People are taking a more expansive view of what a family is," said Chrisler (2016). "But for any family that doesn't fit the 1960s

Ozzie-and-Harriet mold, slow and steady doesn't feel fast enough", as quoted in ABC News (Berman & Francisi, 2010, para. 3).

### **The Worldview Perspective**

It is extremely important for any therapist practicing due diligence in his or her craft to understand the ever-changing world. It is imperative the therapist grasp the multiple interlocking phenomena (Goldenberg & Goldenberg, 2008), the pluralistic view of family, gender roles, ideology, and certainly family structure. Being a therapist who leans heavily on the narrative approach to counseling, it is also critical to identify the significance of the ever-changing narrative or story within the family.

In today's rapidly changing society, family definition continues to evolve in complexity and diversity representing:

A multiplicity of cultural heritages, each may be considered a natural, sustained social system with properties all its own – one that has evolved a set of rules, is replete with assigned and ascribed roles for its members, has an organized power structure, has developed intricate overt and covert forms of communication, and has elaborated ways of negotiating and problem solving that permit various tasks to be performed effectively. (Goldenberg and Goldenberg, 2015, p. 1)

Goldenberg and Goldenberg (2008) believed that within this system, relationship, "microculture" (p.1) there existed a multitude of interlocking phenomena such as race, ethnicity, and social class membership. They also included family life cycle stages, the number of generations within the country, and the physical and mental health of its

members. Lastly, they spoke to sexual orientation, religious affiliation, and level of educational attainment. The financial security and family belief systems were included in the phenomenon listed. It is to this end that definition of family becomes clearer.

Of the eleven interlocking phenomena or a person's history, culture and belief systems, three of the ideas stand out in this therapist's mind, while recognizing and maintaining their connection to the rest: the ideas of religious affiliation, sexual orientation, and family values and belief systems. Being an advocate for a new definition of identity, I believe an individual is comprised of all said phenomena, creating a symphony of sound that no other individual can recognize. As if, in illustration, it is a sound unto itself, a sense of being or music from its parts, its instruments, and even the musicians behind each instrument being played, create a cacophony of sound. It is this picture or illustration that plays an integral part of the formation of theology surrounding family for this therapist.

Religious affiliation, spiritual journey, and a sense of something bigger in life attaches to the roots of a being. It sways, swings, controls, mobilizes, as well as impedes the individual to growth or connection within the family. A study examining whether religion had a beneficial effect on family life sites that, which followed more than 200 married men and women of 20 different religions living in urban settings, found that those who were religious reported that they had stronger families due to community support and organized religion (Abbott D, Berry, M & Meredith W, 1990).

Sexual orientation or gender roles and ideology (Goldenberg & Goldenberg, 2008), has come center stage in the last several years of not only world news, but also

entertainment, workplace, politics, the church, and the family. The genesis or beginning of changing views was best described by; “Males and females are indoctrinated from early in life into different gender based role behavior in the family” (Goldenberg & Goldenberg, p. 5). Tradition played a disparaging part in the creation of roles in society. “Gender shapes our individual identity and expectations, our role and status within our family, and the real and perceived life choices open to us” (Haddock, Zimmerman, & Lyness, 2003, p.34).

Goldenberg and Goldenberg (2008) elaborated more on this concern within family studies: “Men traditionally played the more important role in most heterosexual families; a man’s career moves and personal interests were apt to be prioritized; less was expected of him carrying out household chores; he was likely to be granted the major (or final) influence in family decisions; his leisure time and discretionary spending were given primary attention; and he was expected to have less emotional investment in family relationships” (p.9).

Within Christian thought, family values and belief systems have forever served as an integral part of defining humankind within the family structure. Marcelina Hardy (2017) writes of four primary areas that were influenced by family values:

1. Establishing a Foundation for the Family – provision of stability, support, and comfort.
2. Influencing Decision Making – choices, direction, and structure.
3. Guidance for Raising Children – burden of raising responsible and conscientious children

4. Protection from Outside Influences – peer pressure, moral compass. (Hardy, 2017, p 43)

The world perspective on family and subjects within, could challenge and sway public and personal conviction in enormous ways. The facts presented, if left to stand alone, leans one to integration of Christian thought and science. It is here that perhaps, entertainment of a reconciled approach to family might be considered.

### **Biblical Perspective**

As a therapist of faith, clearer definition is called for in relation to a Biblical perspective on family. While there are multiple definitions, differing understandings and changing positions throughout the world of family studies in academia, mandates the Christian therapist to bring a clearer understanding of family considering Biblical revelation.

In this section, clarification is given to the identified theological principles of the family. They are all relevant and pertinent to not only the family, but to individuals and couples in committed relationships as well. There is no better place to start than in the opening words of God in Genesis 1:27-28:

Then God said, Let Us make man in Our image, according to Our likeness; and let them rule over the fish of the sea and over the birds of the sky and over the cattle and over all the earth, and over every creeping thing that creeps on the earth. God created man in His own image, in the image of God He created him; male and female He created them. (Genesis 1:27-28 NASB)



In these first words, God revealed the first of five principles in defining the family. Humankind was created in the image of God, and with this comes, identification.

**Principle of creation (Imago Dei).** Humankind was made in the “image of God” (Genesis 1:27). First, the passage communicates a God that is actively involved in humankind’s creation, i.e. “he created”. Secondly, Scripture describes as to what God had done, i.e. “in the image of God created him”. But how did one understand this statement? What does the “image of God” look like when God has remained unseen?

In the *New Defender’s Bible*, Henry B. Morris (2006), clarified the meaning of image:

*...in our image.* God is, as it were, taking counsel here with Himself, not with angels, since man was to be made in the image of God, not of angels, therefore, implied human likeness to the triune Godhead. Plants possessed a body, and animals a body and consciousness. Man, was not only to have a body (of the created “earth”) and a consciousness (of the created “soul”), but man was also to possess a third created entity, the image of God, an eternal spirit capable of communion and fellowship with his Creator. (Morris, 2006, p. 24)

Physically, while man could not have the same body as God, since God was a spirit, (John 4:24) he still possessed the image of God. Morally, humankind was created in righteousness, in perfect innocence, and a reflection of God’s holiness. God stated following this creation, that what he made was “good” (Genesis 1:31 NASB).

Hoekema (2017) best described the mental attributes of image saying:

Mentally, man was created as a rational, volitional agent. In other words, man can reason and man can choose. This reflects God's intellect and freedom.

Anytime someone invents a machine, writes a book, paints a landscape, enjoys a symphony, calculates a sum, or names a pet, he or she is proclaiming the fact that we are made in God's image. (Hoekema, 1986)

"Then the LORD GOD formed man of dust from the ground, and breathed into his nostrils the breath of life; and man, became a living being" (Genesis 2:7 NASB). In this passage, God gave breath to man. In this moment, God passed his image into humankind. In this thought, a clearer definition of "image of God" took place. Outlining this helped in the understanding:

1. God gave mankind breath (Genesis 2:7)
2. God gave mankind a material
3. God gave mankind an immaterial setting him apart from the natural world, i.e. animal world.
4. God gave mankind enablement to be able to commune with his maker.  
Mentally, morally and socially.
5. Mentally, mankind as a rational and volitional being, chose, reasoned and to thought freely.
6. Morally, mankind sustained a conscience as well a moral compass able to choose and not choose a life free from or immersed in right and wrong choices.

7. Socially, mankind enjoys fellowship, communion with others as well as with God (Genesis 3:8, NASB)

John Piper (1971), pastor and teacher stated,

...man is in the image of God means that man as a whole person, both physically and spiritually, is in some sense like his Maker. Just what the nature of this likeness is, we are not told. But we are told what really matters: even as sinners we bear God's image. Because of this image in us, we have dominion over all the earth and we have a right to live out our days upon the earth. (Piper, 2011, pp.53-76)

This image, this transfer of holy, invisible, social, moral, and volitional being into mankind, could not be overlooked. This touch of grace by an eternal God led one to consider, not only the image of God, but also the interaction of the tri-unity with mankind, as portrayed in the relationship of the trinity.

**Principle of relationship.** The second principle of defining family rested in relationship. Relationship, especially in the Godhead, i.e. being one and yet maintaining uniqueness, individuality, and being. This principle could best be described in the relationship of God, the father, God, the son, Jesus Christ, and God, the Holy Spirit. They were known in theology as the trinity or tri-unity. This tri-unity described the mystery of marriage and of family. Three but one. One but three. This mystery confounded the minds of theologians for centuries past and certainly, centuries of the future (Sanders, 2010, pp. 7-26). The relationship of Father, Son and Holy Spirit is but a model of what marriage, family and relationship aspired to achieve. In perfect unison, unity of mind

and heart and purpose, and nature, the tri-unity of God was a showcase for the home, as will be more clearly defined further in this chapter.

The word, trinity, presented a mystery. It was not found throughout Scripture, yet was delineated throughout, in concept. From the Hebrew Scriptures to the New Testament of Jesus Christ, words such as “us” and “our” were used interchangeably, about, God (NASB Bible). One example would be Genesis 1:26-27, “Let us make humankind in our image, according to, our likeness.”

Charles Ryrie, professor of theology at Dallas Theological Seminary stated:

Trinity is, of course, not a biblical word. Neither are tri-unity, trine, trinal, subsistence, nor essence. Yet we employ them, and often helpfully, in trying to express this doctrine which is so fraught with difficulties. Furthermore, this is a doctrine which in the New Testament is not explicit even though it is often said that it is implicit in the Old and explicit in the New. But explicit means “characterized by full, clear expression,” an adjective hard to apply to this doctrine. Nevertheless, the doctrine grows out of the Scriptures, so it is a biblical teaching. (Ryrie, 1999, p. 58)

**Principle of redemption.** It is in the creation, from a world, empty and void that God began the process of redemption. In this picture of emptiness, Christ being present in creation, simply “was” (Colossians 1). Christ is eternal in existence as well as forever. He is the same yesterday, today and forever (Hebrews 13:8). He came into this world to redeem mankind from sin, fallen lives, and the results of living outside his loving and guiding hand. “God commended His love toward us, in that while we were yet sinners,

Christ died for us” (Romans 5:8, NASB). He stood at the proverbial valley of decay to raise mankind to the pinnacle of glory, His redemption. In reflecting the image of God individually, hope was brought into marriage and family, even when it was thought there was no longer hope. In resonating the hope of God through His incarnate work, there lay the possibility and certainty of God’s redemptive plan. The cross and shedding of blood became the promise, the hope, and the certainty of his abounding redemption for humankind.

Relationship and marriage and family were an ideal setting to view redemption at work. Forgiveness, restoration, grace, and hope enveloped all circumstances concerning His children and their families and marriages.

An example in the Bible of God’s redemptive plan was seen for His people. After Judah, the people of God, turned their back on God and anything that reminded them of Him in Zephaniah, he wrote, “The LORD your God is in your midst, A victorious warrior. He will exult over you with joy, He will be quiet in His love, He will rejoice over you with shouts of joy” (Zephaniah 3:17, NASB). God’s grace, His love, His praises for His children, and yes, even His shouts of joy permeated Scripture for His people Israel, His church and for humankind.

In Him we have redemption through His blood, the forgiveness of our trespasses, per the riches of His grace (Ephesians 1:7, NASB). “And not only this, but also, we ourselves, having the first fruits of the Spirit, even we ourselves groan within ourselves, waiting eagerly for *our* adoption as sons, the *redemption* of our body” (Romans 8:23 NASB). It was through this redemption Christ stood ready to pour redemption into the

home, into a marriage, and into His church. The family and marriage, focused on this pinnacle of redemption, discovered hope when there was no hope, grace when there was no foundation for forgiveness, and celebration when all the party favors had been stored.

Redemption introduced forgiveness into the marriage. Ryan Howes (2009) wrote, "The mental and physical health benefits of forgiveness are well established. But for some reason, it's much easier said than done" (para. 4). He continued and listed four elements important to achieving forgiveness in the relationship: Express the emotion, understand why, rebuild safety, and only after one accomplishes these first three, then, let go.

In expressing the emotion, Howes included elements of expression, "Whatever the crime or injustice or violation, the forgiver needs to fully express how it made her feel. If the transgression elicits anger or sadness or hurt, those feelings need to be deeply felt and expressed" (Howes, 2008, para. 5). A full expression of feelings, heart, and mind took place and led the forgiver to understand the meaning of the issue.

Understanding the meaning was what the brain sought to achieve, some level of understanding of the situation, even of words said. As the story was told, emotions shared, the forgiver then could admit to the reality of circumstances or even the ambiguous details. Howes (2008) related, "Even an acceptance of randomness can be a sufficient paradigm" (para. 6). It was, in the walking on the road of emotion and understanding, that Howes stated there is no order or algorithm to follow, however, the forgiver begins the rebuild safety.

Rebuilding safety was a tenuous walk. It was on the perpetrator to assure the forgiver that the act would not reoccur. Howes (2008) stated, "The forgiver needs to feel a reasonable amount of assurance the act won't recur. Whether it came in the form of a sincere apology from the perpetrator, a stronger defense against future attacks, or removal from that person's influence, safety needed to be re-acquired" (para. 7).

It was when these first three elements were satisfied, in any array or order, the forgiver could let go. While not a three-step process, these elements were tantamount to seeing the process of letting go occur.

Discovering the elements of finding forgiveness with God, confession, expression, understanding, and repentance, did the God of this universe help the broken let go and rebuild. What better picture of redemption could one discover?

**Principle of permanence or covenant.** With the backdrop of God's redemptive plan, His grace and willingness to embrace His children, lies the concept of covenant. The establishment of covenant began with His commitment to the nation of Israel and was the foundational focus in developing a theology of the family. In fully understanding the depth of a covenant, it was impossible to define without understanding the unconditionality of the term (Balswick & Balswick, 2007, pp. 18-19). Anderson and Guernsey (1985) emphasized the unconditional quality:

It is covenant love that provides the basis for family. For this reason, family means much more than consanguinity, where blood ties provide the only basis for belonging. Family is where you are loved unconditionally and where you can count on that love even when you least deserve it. (p.40)

The question arises as to how and where you could use covenant as a metaphor for marriage and family relationships. McLean (1984) attempted to answer the question.

He listed seven ways:

1. People are social and live in community
2. The basic unit of family and of covenant is the dyad
3. People living in community experience struggle and conflict as well as harmony
4. People living in covenant must be willing to forgive and be forgiven by one another
5. People living in covenant must accept their bondedness to one another
6. People living in covenant accept law in the form of patterns and order in relationships
7. People living in covenant have a temporal awareness as they carry a memory of the past, live in present, and anticipate the future. (pp. 4-32)

Covenant love is foundational in marriage and relationships if those relationships are going to work. It is as if a stake is driven into the ground, a commitment made that stands stronger than the sentimental love or romantic love that permeates our media and entertainment world. It is a stake of commitment that is remembered, revisited, and tears shed upon, that solidifies the home, marriage and family (Balwick & Balwick, 2007, p. 68).

**Principle of oneness.** At the beginning of creation God saw one thing that was not good: "The Lord God said, 'It is not good for the man to be alone'" (Genesis 2:18).



God identified an incompleteness in His creation, and the answer to this was Eve. Eve was created (and with her, the order of marriage) to make humanity and all of creation strong. Through vulnerability comes strength, for God's "power is made perfect in weakness" (2 Cor 12:9). Paradoxically, marriage makes people stronger by making them more vulnerable. Vulnerability allows for intimacy—or as the word is sometimes rendered, *into-me-see*. Marriage exploits the fact that humans are not opaque, but are full of holes. Eyes, mouths, ears, sexual orifices are the channels for intimate communion.

Through our cracks, love seeps in. A crack was how it all started, when God took part of the man's side and made a woman from the part he had taken out of the man (Genesis 2:21–22). Ever since then, the man and the woman have been trying to get back together, seeking to recapture their essential oneness. The act of sex goes only so far toward this goal. The more perfect solution is marriage. God brought the first woman to the first man, and this has been His main business in the world—drawing people together into unity. Marriage is a living demonstration of the extravagant intimacy into which God wishes to draw all people (Mason, 2008).

The concept of oneness is not new. The author of the book of Genesis used it, writing, “For this reason a man shall leave his father and mother and shall be joined to his wife, and they shall become one flesh and they shall become one flesh” (Genesis 2:24, NASB). The apostle Paul referred to it, this mystery is great; but I am speaking regarding Christ and the church (Ephesians 5:31–32, NASB).

This unity, this duality, this relationship that man and woman enter is a solemn one, one not meant to ever end, and certainly one that portrays the relationship that Christ has with His church. Seager wrote, “They are to form one seamless new identity: one flesh” (Seager, 2014, para. 3). They are not considered two people merely living together, conducting business together, or experiencing life together. They are one flesh, and what God has joined together, let not man [or woman] separate.

### **Summary of the Family**

Marriage and family, as well as singleness has changed in definition significantly over the centuries. It is imperative that this therapist understands and fulfills the burden given him to be a therapist. Additionally, one who exemplifies in his education, therapeutic practice and conviction of heart, the Biblical model of family. It is to understand and convey the creation of human kind and the fulfillment of the “*imago dei*”, the image of God (Morris, electronic). Family is a system of relationships, dyads, triads, all working together towards success and fulfillment. This principle of relationship is foundational in research to establishing richness within the home (Ryrie, 1999, p. 58). Redemption provides the backdrop for the interaction of not only couple in marriage but also for the entire family as they participate together as a unit. A marriage built upon covenant or permanence sets the standard for longevity and hope. (Balswick & Balswick, 2007, p.20) And finally the principle of oneness, is pivotal throughout the establishment of home centered on God.

The family defined is ideal and almost altruistic in definition but provides a starting place for the therapist to launch the practice of his or her mental health skills. In

chapter three a review the current and past literature that has been the basis of these past two chapters and will serve as a foundation for application.

## **CHAPTER THREE**

### **CONFRONTING THE QUESTION: LITERATURE REVIEW**

When confronting the question, are there mental health effects on the family because of multiple sclerosis (MS), literature encompasses a general view of chronic illness to a more isolated view of the effect of multiple sclerosis. The loved one, a family member, and even a friend is affected mentally, when MS invades the life of their friend or family member. To understand this secondary impact, one must understand the primary impact on the patient with the disease.

#### **Chronic Illness (Including MS)**

The National MS Association (2016) published a brochure that speaks to both the cognitive and emotional effects on this topic: Cognitive means of or relating to cognition which refers to a range of high-level brain functions including the ability to learn and remember information, organize, plan and problem-solve, focus, maintain and shift attention, understand and use language, accurately perceive the environment, and perform calculations.

Cognitive changes are a common symptom of MS — approximately half of all people with MS develop problems with cognition. Loss of myelin around nerve fibers can cause difficulty with transporting memories to storage areas of the brain or retrieving them from storage areas. In MS, certain functions are more likely to be affected than others are:

Memory (acquiring, retaining, and retrieving new information)

Attention and concentration (particularly divided attention)

Information processing (dealing with information gathered by the five senses)

Executive functions (planning and prioritizing)

Visuospatial functions (visual perception and constructional abilities)

Verbal fluency (word-finding)

Emotional Effects of MS may have profound emotional consequences. At first, it may be difficult to adjust to the diagnosis of a disorder that is unpredictable, has a fluctuating course, and carries a risk of progressing over time to some level of physical disability. Lack of knowledge about the disease adds to the anxieties commonly experienced by people who are newly diagnosed. In addition to these emotional reactions to the disease, demyelination and damage to nerve fibers in the brain also result in emotional changes: Examples include healthy grieving, mood changes, depression, stress, generalized anxiety and distress, moodiness and irritability, pseudobulbar Affect (PBA), inappropriate behavior, and sleep disorder (NMSA, 2016, para.1-5).

The client with MS is often unaware of the emotional symptoms in their life. Mood changes can be confused with exhaustion, depression with feeling physically spent, and anxiety about worry for family and self. Later in this chapter, literature on depression as an effect from MS will be examined more closely. The effects of chronic illness, such as, cancer, MS, heart disease, and lung diseases, all can affect the family, as well as the client emotionally and psychologically.

The American Association of Marriage Family Therapy (2015), delineated such in their website. How can chronic illness effect the family? AAMFT details the following:

1. Daily routines change because the limitations of the ill member and the demands of treatment may require that others be more available.
2. Families may need to share caregiving responsibilities; this helps all members feel they are contributing to a loved one's welfare and protects any single member from caregiver fatigue.
3. Family members may experience strong emotions, such as guilt, anger, sadness, fear, anxiety, and depressed mood. These are normal reactions to stress. It is useful to talk about these emotions within the family.
4. The ill member may need to find ways to be as independent as possible, given the limitations the illness causes.
5. Despite the demands of the illness, families need to work hard to maintain a sense of normal life. This can benefit the ill member, as well. It may help him or her integrate into family life more and reduce the sense of guilt felt regarding the demands the illness places on the family (para. 1-4).

In summary of the AAMFT findings, chronic illness within the home changes daily routines, shifts the sharing of caregiving responsibilities, family members experience strong emotions, and the family needs to work hard to maintain a sense of normal life (AAMFT, 2015).

## Multiple Sclerosis and the Family

Lisa Esposito (2015) wrote, "This disease shows up in your household, moves in, spreads its junk all over and doesn't leave. It means everyone has to develop a relationship with this intruder" (para. 1). Following are a list of both general and specific MS effects on both family and the afflicted:

**Ups and downs.** Allison Shadday (2007) elaborated on handling difficulties of MS. She spent years primarily working with both people struggling with the disease and the families.

Shadday (2007) described the four types of MS clearly and concisely: relapsing-remitting, secondary-progressive, primary-progressive, and chronic-progressive MS, all the intrusive intruders in the lives of men and women worldwide. She annunciated the common symptoms of the disease clearly, helped the reader walk in the shoes of the afflicted, defused the myths, and helped the MS patient and family come to grips with the disease. Perhaps the strongest point she makes is learning to accept the disease. Acceptance of the disease changes multiple areas of the afflicted person's life. Shadday lists several of those areas below:

1. MS is no longer the focus of your life. By accepting the disease, one moves on to new things, goals and dreams.
2. Sadness, anger, and disappointment are occasional emotions, not a way of life.
3. Although you're optimistic, you accept that the disease may progress in the future.

4. You continue to make plans, based on your current level of ability, with the understanding that these plans may need to be altered.
5. In the event of physical impairment, you can readjust your goals in work, play, and relationships to match your ability.
6. You are no longer consumed by fear of the future.
7. You are willing to accept help from others, while finding your own way to reciprocate.
8. Regardless of physical limitations, you strive to maintain a positive self-image.
9. You view your MS as an added challenge in your life and not merely as a reason for all your problems (p. 30-31).

It is important to understand that acceptance is not total transformation, but often masked behind the pains and losses of the MS disease. Acceptance is the first step to a healthier lifestyle.

**Tangible effects of MS on the family.** Julie Yoon Moberg, Dorte Larsen and Anne Brodsgaard (2016) presented data pertaining specifically to those persons 18-25 years of age, specifically family members of an MS patient, who demonstrated physical disabilities and cognitive dysfunction related to MS (and other chronic diseases). They found the side effects of MS and other chronic diseases complicated parenting and some side effects could cause difficulty in a family.

The study found the MS patient was often unable to maintain their profession creating income issues, in either taking lower paying jobs or in losing their



employment. The family interactions changed as keeping up the house took longer or could no longer be done. There was a change in family dynamics as well, when fatigue constrained the ability of the patient to participate in family activities. Finally, separation from the spouse could occur based on the effects of MS (Moberg et al, 2016).

In addition to these tangible consequences of MS, the research showed that there were also psychological effects of living with a chronic disease. Life stressors seemed to have a greater negative impact overall on the family. Stressors were magnified by persistent thoughts, especially by parents with the disease, that they were not living the lives they imagined for themselves or that their parenting was not the parenting they envisioned (Moberg et al, 2016, p. 1). Their study served as poignant segue to the general effects of MS on the family.

There were several excellent research studies that supported and validated the findings of this project. First, the MS International Federation (2016) reported cognitive difficulties as invisible symptoms resulting in family members of the afflicted misinterpreting behaviour and reactions. In addition, daily memory issues, problem solving and concentration are seen as not listening, being uninterested, and a general non-commitment to cooperation (Moberg et al, 2016).

Second, it is important to return to the study done by Moberg et al, (2016) in which they interviewed 14 young adult members of MS families. They addressed eight specific subthemes that surrounded the essence of striving for balance between caring and restraint, the two main themes of their findings. The care and safe-keeping for a family

member with MS was debilitating and exhausting. Moberg et al, delineated these two essential themes pertaining to the care of a loved one with MS.

Caring as a theme can be summed up as assuming responsibility within the home and before their loved one with MS. Additionally participants worried that their actions in life might have a negative impact leading to worry and guilt. Many participants choose health-related careers allowing for the experience to dictate their futures. Finally, the participants voice an advantage of being responsible, in terms of organizing their education and private lives. One participant wrote “I’ve always been very structured as far as I can remember. I like to be on top of my appointments and tasks and write them in my planner. I like to know what I’m doing next year and what’s coming up. But my mom is the same way and with a chronically ill family member you must plan a lot and be structured. Things revolve around my dad because he needs to live with a structured routine” (Moberg, 2016, pp. 4-9).

Restraint in concealing feelings and desires has led to not having the ability to discern one’s own feelings and lacking the ability to express said feelings. Moberg, (2016) noted participants’ concerns for their parents were so profound, parental relationships were affected and thus, participants kept certain feelings inside to protect the parent with MS. Most patients kept resentments bottled up inside and rarely argued with their parents. Two of the participants suffered from depression and anxiety. They said they had become, “...so accustomed to caring for their parents during childhood that only when they entered young adulthood did they gradually recognize the deep and pervasive physical and emotional consequences of this care” (p. 7). Of all these

participants interviewed, there was a deep and moving desire to blend in within their friends and community so they were not noticed, thus protecting them the shame of their ill loved one. Many of the participants were ignorant of their understanding of the disease. Even though the parent had been sick for some time, many expressed a lack of pertinent knowledge to sustain themselves through the disease crisis.

In summary, Moberg et al (2016) wrote, "Participants cared for their parents by assuming responsibility, experiencing worry and guilt, choosing health-related educational fields, and developing strategies making them responsible" (p.7). Participants experienced restraint by concealing their feelings and desires, developing anxiety and depression, experiencing shame, and lacking openness and knowledge about MS to avoid distressing their parents.

**Specific effects of MS on the family (depression and anxiety).** The National MS Society stated that depression, in all its various forms was one the most common symptoms of MS. Research supported and affirmed the presence of depression and anxiety and their prevalence among those afflicted with the disease. (NMSS, 2016) Unipolar or major depression was prevalent among people with MS, reported R.J. Siegart and D. A. Abernathy (2005).

Symptoms observed included persistent sadness and the participants developed a negative self-image. A persistent feeling of guilt and self-blame was present as well. Study participants also experienced problems sleeping, had fatigue and loss of interest in their normal activities. Other effects included loss of appetite, or the converse,

psychomotor issues, reduced concentration, and suicidal thoughts (Siegart & Abernathy, 2005, pp. 469-497).

Schiffler (1990) noted, "...most studies reported a higher incidence and prevalence of depressive symptoms in MS compared with control group with a different neurological illness" (Schiffler & Wineman, 1990, pp. 1493-1497). When plagued by the demonstrative affect, people with MS demonstrated anecdotal and marked decrease in their ability to handle the accompanying depression with their disease.

In this article, Schiffler et al (2010), added several studies affirmed marked depression among those with MS:

Minden and colleagues examined 50 patients with MS selected quasi-randomly... reported that 54% of their sample met the research diagnostic criteria (RDC) for major depression" (Minden, 1987).

Joffe et al assessed 100 consecutive patients attending an MS clinic in Canada using the RDC for major depression and reported a life prevalence of 42% (Joffe, 1987).

In a study of 221 consecutive patients in Vancouver, BC, Sadovnick et al reported a lifetime prevalence of 50% using a structured psychiatric interview (Sadovnick, 1996).

Chwastiak et al undertook a mail survey of 1374 members of the Multiple Sclerosis Association of King County, WA, with 739 responses. Of the 739 responses, 42% of that sample had "clinically significant depressive symptoms"

according to the Centre for Epidemiological Studies Depression Scale (CES-D) and 29% scored in the moderate to severe range (Chwastiak, 2002).

Schiffler et al (2010), in his review of MS and the prevalence of depression among those with MS, raised for this researcher many questions and assertions of how depression appeared in the MS patient, including suicide, fatigue, anxiety, and the apparent cognitive impairment. In addition, they concluded depression is common among those with MS, with rates as high as 20 percent reported, and lifetime rates of 50 percent (pp. 1493-97).

In a study done by the Department of Measurement and Health Information Systems, World Health Organization, Geneva, Switzerland, studies have shown that there is an increased risk of having major depression in people with one or more chronic diseases. The degree to which these comorbid states exist at the global level has not been shown. With a growing elderly population, and the associated increase in prevalence of chronic medical conditions, a concomitant rise in the prevalence of depression is to be expected. In fact, projections indicate that after heart disease, depression is expected to become the second leading cause of disease burden by the year 2022 (Moussavi, Chatterji, Verdes, Tandon, Patel, & Ustun, 2007).

Another result of MS, was the impact on children of an MS client. As will be delineated in chapter 4, this case study illustrated the significant impact of MS and its accompanying depression as a life-changing experience for the child. Children experienced stress, worrying about the health of the parent with MS. They helped with household chores that were time-consuming and helped with the parent's personal

hygiene. The child's social life was negatively impacted and they feared bringing friends home, due to their parent's disability (Stachowiak, 2013, para. 7). However, Stachowiak reported a blessing accompanied the stress. She stated some children reported they developed more self-reliance, more independence, more dependability, and became more helpful, and more sensitive to the needs of others. In short, it seemed like having a parent with MS helped children mature more gracefully into a better citizen of the world (Stachowiak, 2013, para. 8).

### **Conveying Hopeful Outcomes with EFT and Attachment Model**

The outcomes of Emotional Focused Therapy or Emotional Focused Family (EFFT) or Couple Therapy (EFCT) were profound as stated in the research. The research behind EFT supported the need for emotions to flow, resonance to be realized, and with attachment theory, it offered a map of love and belonging (Johnson, 2004, p. 244). Johnson wrote that it was emotional experience and expression that played a large part in organizing and regulating social interaction, in therapy, and in the family (Johnson, 2004, p.243). "EFFT is part of this movement toward the integration of attachment theory and the music of the attachment dance, emotion, into the family therapy field" (Johnson, 2004, p.244).

Working with the family through use of triadic and dyadic relationships, the therapist and couple and/or family came to understand one another better. Through open communication, walls were lowered, emotion was allowed and paid attention to, and perhaps, for the first time, each within the relationship heard and comprehended one another for the first time. Using the EFFT model, there was a decrease in distress in

the relationship, interaction rose in successful ways, and there was empirical evidence of positive effects of this therapy, followed the family or couple for years (Yalom, 2011, p. 2).

The strengths of EFT (EFFT, EFCT) are many:

1. Its assumptions, strategies, and interventions were clearly delineated and specified. It was brief and usually implemented in 8-20 sessions.
2. It received empirical support for use in general and specific populations. (i.e. parents of chronically ill children, research on process change, and depression)
3. The process through therapy was clearly outlined in three stages and nine steps.
4. Clear theoretical base: Theory of change and theory of adult love (attachment process)
5. Applicable to many kinds of clients:

“It is used for a wide variety of couples and partners, including partners from different cultures and social classes, gay couples, older couples, couples suffering from chronic illness (Knowal, Johnson and Lee, 2003), depression and anxiety disorders such as PTSD (Johnson, 2002). There was preliminary evidence that EFT reduces depression in partners. (Dessaulles, Johnson & Denton, 2003, pp. 8-9)

**EFT and Its Use in Depression Clients.** In a study by Rhonda Goldman, Leslie S. Greenberg and Lynne Angus (2006) these therapists looked at 43 adult patients suffering from Major Depression Disorder over an 18-month period. They divided the group in half and applied two types of therapies, EFT and Client Centered Therapy, hoping to discover positive effects of using EFT as their therapy modality. The results were profound:

EFT treatment showed superior effects across 18 months in terms of depression relapse and greater number of asymptomatic or minimally symptomatic weeks, and the probability of maintaining treatment gains was significantly more likely in the EFT treatment in comparison with the CC treatment.” (Goldman, Greenberg, & Angus, 2006, p. 103)

The following were several of the positive results of this study: Results include, reduction of depression, improvement of self-esteem, reduction of general symptoms of distress, reduction of interpersonal problems, not experience first relapse of depression, for a significantly longer period and on average, the client would experience a significantly greater number of well-weeks (successive addition of weeks where clients reported minimal or no depressive symptoms (Goldman et al, 2006, pp. 103-112).

In working with the primary couple and family of this research study, EFT has not only set the foundation for open communication and resonated emotion, but also for a future of familial growth and strength, amid the client’s chronic illness.



## **Conveying Hopeful Outcomes with Narrative Therapy**

The strongest outcome of the use of narrative therapy was that of allowing for the story or what Epston (1973) called the narrative metaphor, to be told and heard. It allowed for story, exposure of emotion, feelings, issues, and construction and deconstruction of issues. The key word throughout the theory was that of story.

Nichols (2013) stated, "By externalizing problems, deconstructing pessimistic life stories, and conveying unwavering confidence in their clients, narrative therapists have constructed a powerful recipe for change" (Nichols, 2013, p.282). There are two powerful ingredients in narrative therapy. First, Denborough (2001) would encourage the use of:

Narrative Metaphor – freeing people from their oppressive cultural assumptions and empowering them to become active authors in their own lives. It is to give open space for new and more constructive views of themselves (p.273). "The narrative metaphor takes in what is often referred to as the temporal dimension. It encourages a focus on the ways in which the events of people's lives are routinely coded into time, on the ways in which events are read into unfolding accounts of life." (Denborough, 2001)

Secondly, Nichols (2013) would add:

Externalization of Problems – Instead of looking inside families for the source of their problems, narrative therapists look outside to the toxic effects of cultural narratives. The obsession with the internal is then set aside for the effects and

the ongoing story of the negative in a person, couple or family life. (Nichols, 2013, p. 272)

These first two ingredients of Narrative Therapy allow for the client to become authors or conductors of their own story or song. Open space vice that of closed, and while other therapies may lead to an inside examination, as in psychoanalysis, narrative seeks to take the client outside his or her toxic events. In illustration, NT looks across the room at an open life, is creative and expansive. Michael White (1995) wrote:

The discourses of pathology make it possible for us to ignore the extent to which the problems for which people seek therapy are the outcome of certain practices of relationship and practices of the self, many of which are actually informed by modern notions of “individualism” and are so often mired in the structures of inequality of our culture, including those pertaining to gender, race, ethnicity, class, economics, and so on.” (p.115)

Narrative therapy was beneficial, in that, it allowed for the story to be told, constructed, and deconstructed for its positive and negative effect on client. It fostered a sense of partnership with therapist. In a family setting, as story was told, it allowed for restructuring, or retelling. Story allowed each family members viewpoint into the narrative.

It is, as Nichols (2013) pointed out, “about helping clients identify and challenge the ubiquitous but commonly unexamined prejudices that permeate society and make self-worth and harmonious relating difficult” (p.283). From deconstruction to reconstruction, from confusion to meaning, from culturally saturated to client-based

outcome, narrative therapy seemingly awoke the client and/or family to new horizons and growth.

### **Summary of Literature Review**

The foundational truth of this thesis lay in the definition of family, the therapeutic steps taken to resolve, address, and heal the brokenness caused by a family member with chronic illness and its accompanying depression. As stated throughout this chapter, family members experience a range of response and reaction to MS in the home. From problems sleeping, eating, fatigue, sadness, loss and multiple mental health issues.

Emotion Focused Therapy with Attachment Theory and Narrative Therapy showed promise in addressing the ramifications of chronic illness in the home. In the next chapter, application of these results applied in the case study will be discussed.

## **CHAPTER FOUR**

### **JAMES AND MANDY FAMILY CASE STUDY**

James and Mandy S. and family have provided all information for the study as well as each family member within. Other than reported assessments, no collateral research has been done to ascertain personal or family information. James and Mandy S. and family willingly participated in several assessments allowing for a case formation and recommendations. James and Mandy S. (from this point referred to as James and Mandy) have completed the following assessments and evaluations: Myers-Briggs Type Indicator (Keirsey & Bates, 1978), Riso-Hudson Enneagram Type Indicator (RHETI Version 2.5, Riso, 1990), Genogram (McGoldrick & Gerson, 1985), Beck Depression Inventory (BDI), and multiple communications.

#### **Introduction to the Family**

James and Mandy were married on April 25, 1998. They currently reside in western United States with their children, Bobby (17), Bobbie (13) and Tommy (7). They have lived in the western United States for many years, are active in their local church, in their community and volunteer regularly to raise awareness about MS and the Wounded Warriors Project. James was diagnosed with Multiple Sclerosis (remitting/relapsing) approximately four years ago, is currently unemployed, his wife, Mandy works for their church. They are both actively involved in life, and Mandy is the primary wage earner in the home because of James's illness.

## Genogram (James and Mandy Family) (Figure One)

As this therapist seeks to better understand James and Mandy's familial history, it is best observed initially through genogram development as shown in Figure 1.

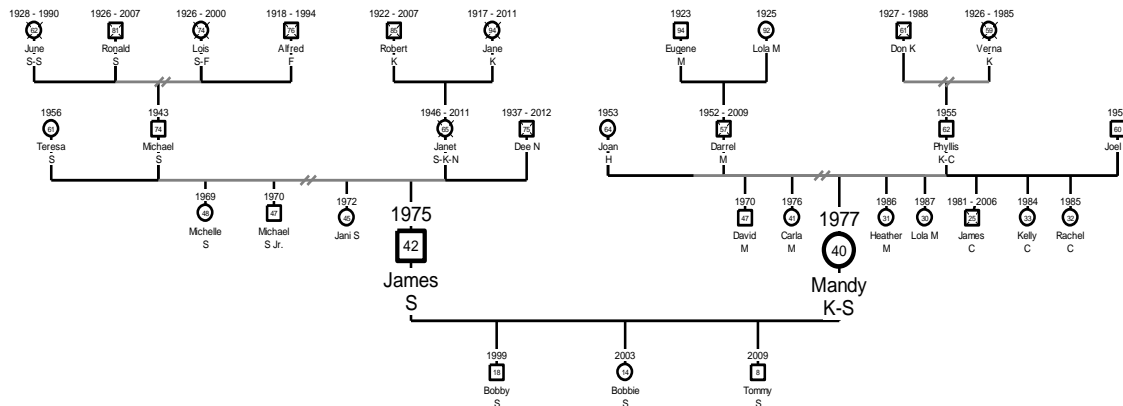


Figure 1 represents James and Mandy's family through three generations. James (42), Mandy (40), Bobby (17), Bobbie (13) and Tommy (7). This genogram provides a myriad of information in James's life and the two generations prior to him. Much of the information gathered in Figure 1 has had a direct impact on both he and Mandy's life.

**James.** James was born in Montana, to Janet Smith (d.1937-2011) and Michael (1943-) on 13 March 1975. He is the youngest of three siblings - Michele "Shelly" (1969), Michael Jr. (1970) and Jani (1972). His mother and father divorced in 1988, due to infidelity by his father. His mother remarried to Dee (d. 1937-2002) and father remarried Theresa.

James's life took him all over the Pacific Northwest. He moved in the 7<sup>th</sup> grade, and then immediately to Washington, where he graduated from High School in 1992. In 1993, James enlisted in the United States Navy Reserve, serving until 2005. He moved in

1997, took a short break to go to college in Lynchburg, Virginia, (Liberty University), and then returned with his new wife (Mandy) in 1999. He has since remained.

James's family history has had several themes that are important for this study. Attention Deficit Disorder and learning disorders plagued James throughout his early and late childhood. This struggle clearly defined his days in K-12 school, as well as his days at Liberty University. While he is by nature an extremely humble man, he admits a real hesitancy to succeed due to these ongoing challenges with ADD and acquired learning disorders. His ADD has caused him to struggle with a poor self-image throughout his life. "I am not the best student in the world" (interview), has become more his mantra, and has become an excuse throughout the years. Perhaps his greatest battle has been his family history and the memories associated with it.

Mother (Janet) died of a brain tumor in 2011. Step-father died of Esophageal Cancer in 2002. His older brother, Michael Jr. remains in a nursing home for Multiple Sclerosis (Primary Progressive). Grandparents (multiple) all died from complications with alcoholism and with kidney failure, currently present in two of the family members.

When interviewed, James described his biological family with terms such as "broken" and "sad". When it comes to his own life, he said he has always felt "abandoned (by his father), sterile, not wanted, non-physical, and distant" (James, 2016). His biological father (Michael) and his step mother (Teresa) are his only parents still alive. He and his father worked hard over the years to reestablish some level of understanding and care following years of neglect. Emotional distance still plagues the relationship. His biological mother, Janet, was married two more times following her

divorce to James's father. She was diagnosed with bipolar disorder early in her second marriage, which became one of many family secrets. She died in 2011. Pertinent to this study are the grandparents in James's life, both biological and step-grandparents.

James's father's parents (Ronald and Lois, deceased) were divorced and both had subsequent marriages. Ronald was an alcoholic which led to the early divorce and Lois died of kidney failure, soon after getting married the second time. James's mother's parents (Robert and Jane, deceased) died following years of Robert's abuse on Jane, which led to Jane's cardiac death later in life.

James has one brother (Michael) and two sisters (Michele "Shelly" and Jani), all born to his biological parents, Michael and Janet. Of James's siblings, Shelly (47) is his favorite. They have a good relationship and communicate on a regular basis. His brother Michael Jr. (46) continues to decline from his diagnosis of MS and his sister Jani (44) is a meth-amphetamine addict, diagnosed bipolar, and is homeless, living somewhere in the Pacific Northwest (unknown location).

**Personality.** According to the Myers-Briggs Type Indicator (Myers, Briggs, 2017), James has identified himself as an ISFJ. The MBTI would classify him as an Introvert, Sensing, Feeling and Judgment, personality. He is generally kind, empathetic, traditional, shy, caring, practical, and very loyal. He loves helping and assisting others around him and often assumes a nurturing role in his family and society. He is often self-effacing, unpretentious, has strong moral convictions and a deep-seated sense of social and human duty and purpose. He is very affectionate, committed, and dedicated to his family and friends, often willing to sacrifice his wishes and needs to meet the needs of

others. In the long run, this has led many times to a fair amount of frustration and suffering (MBTI, 2017).

**Faith.** James gave his life to Christ at the age of 21, after his wife invited him to see a play at church concerning Heaven and hell. James lives his faith daily, active in their local church, a behind the scenes volunteer, and an ardent proponent of seeing the homeless employed and active in society. While his health prevents full participation, he continues to reach out, care, and provide as best he can, to the poor. Along with two others, James started and is currently the behind the scenes consultant of a bicycle shop that employs 4-6 homeless men giving them hope and purpose in the community. James passed his faith on to his children and has multiplied it into each. James's wife states, "I really believe that if we had not had our faith in Christ, and the tremendous amount of support from our church family and friends, our marriage would have probably been a casualty" (Mandy, 2016).

**Impact.** James struggles today with severe bouts of depression and anxiety resulting from his diagnosis with Multiple Sclerosis. He has been diagnosed with Adjustment Disorder with Mixed Anxiety and Depressed Mood (Chronic) (American Psychiatric Association, 2013). The specific *DSM-5* diagnostic criteria for adjustment disorder (AD) are as listed below, and are present in James's life: James has emotional and behavioral symptoms consistent AD, symptoms have lasted over 3 months, and his condition has exacerbated his ability to work, be involved with extended social life and certainly his family. His condition is also accompanied by both depressive moods and anxiety (American Psychiatric Association, 2013).



In evaluating and assessing James and Mandy as a couple, one cannot overlook the powerful impact of both James' illness and the resultant adjustment issues, with accompanying depression and anxiety. More of this impact will be addressed in the summary of this chapter.

**Mandy.** Mandy was born in the western United States, on June 20, 1977. Her parents were mother, Phyllis (1955) and father, Darrell (1952-2009). Her parents were divorced when Mandy was 3-4 years old and both remarried. Phyllis remarried in 1981 to Joel Craig (1957) and Darrell remarried to Joan in approximately 1982.

Mandy has one full sister Lola, and six other half-brothers and sisters. They include Carla and David, born to Darrell and Joani; James, Kelly, and Rachael, born to Phyllis and Joel, and Heather, born to Darrell and Connie (Third wife). The emotion and careful response of each sibling varied in conversation. Carla is known to be a "jerk, mean and nasty", while David is adored by Mandy like a full brother. She is very close to Lola, yet Lola was the object of Mandy's father's wrath throughout her life resulting in her running away in high school, never to return. James died at age 26, the result of an Improvised Explosive Device (IED) in Iraq, while serving in the United States Army. She did not elaborate much on Kelly, or her baby sister Rachael. Heather, born to Darrell and Connie became and remains a meth amphetamine addict and alcoholic (Mandy, 2015).

Like her husband, James, Mandy moved several times as child, as well as an adult. She has lived all over the northwest and, Lynchburg, Virginia (where she met James and subsequently married) and then finally settled.

Mandy grew up with an extremely violent father. He was an alcoholic and bipolar (multiple psychotic episodes) leading to physical and emotional abuse. Because of her bipolar diagnosis and abuse by her husband her mother, went into hiding for years. When Mandy was 5 years old, because of a car accident, her father was confined to a wheelchair for life, due to his injuries. When Mandy was 5-6 years old, living on the Olympic Peninsula, she was sexually abused by her 14-year old male cousin. These events marked the beginning of a very difficult journey to find “the definition of normal” in her life. To this day, Mandy remains in ongoing counseling to bring balance to a tumultuous childhood (Mandy, 2016).

**Personality.** According to the Myers-Briggs Type Indicator (Myers, Briggs, 2017), Mandy identified herself as an INFJ (Introvert Intuitive Feeling Judging). She is generally a kind, empathetic, traditional, shy, caring, practical, and very loyal woman. She loves helping and assisting people around her and often assumes a nurturing role in her family and society. She is a caregiver and mother figure for her husband and three children. She is often self-effacing and unpretentious, has strong moral convictions, and a deep-seated sense of her social and human duty and purpose. She is very affectionate, committed, and dedicated to her loved ones, and often willing to sacrifice her own wishes and needs to meet those of others. These traits may eventually end up causing her a fair amount of emotional suffering and frustration.

**Faith.** At the age of 9 years old, while living in Washington, and during a Vacation Bible School, Mandy gave her life to Christ. This act would be the beginning of a life filled with challenges, pain, growth, and opportunity. She attended Liberty

University in Lynchburg, Virginia, where she completed her Bachelor of Science in Psychology. Following her education and James's subsequent illness, Mandy became the church office administrator where she still serves to this day. Due to James's health crisis, Mandy has become the sole financial provider in a house of five, with the accompaniment of multiple animals to this growing family. Just like James's statement of faith, "...if we had not had our faith in Christ..." serves as a pivotal statement of life with Christ as defined by this heroic woman. Mandy does not consider herself a heroine, but simply a woman faithful to her family and God.

**Impact.** Mandy is committed to her marriage, her faith, her children, her church, and God. She has said there have been many times on this road of survival, the temptation to walk away, resulting from James' exhaustion, failure to ad to family, and chronic illness, loomed dark in her mind, yet her faith and hope would not allow her to make the choice. The faces of her three children, the brokenness of a once strong and fervent husband, continues to implore her to draw strength from friends, family, church and God.

**The children: Bobby (17).** Bobby was first brought to my attention by his mother with concerns on how he was responding to his father's new diagnosis of MS in 2013. At that point, Bobby was 15 years old. He had been seen by a family counselor, but the time with that counselor did not prove to be worthwhile for this scared young man. His presenting issue was "my father is going to die" and not having details or a lot of fact, Bobby was completely overwhelmed. Much of what was assessed in these first sessions are discussed in the following.

Bobby, is the oldest of James and Mandy's three children. The youngest brother Tommy, and sister Bobbie. Bobbie is a very good student with no glaring problems socially or educationally. Tommy is a normal child, full of spunk and vigor. The family all attend a local church, are Christ followers, and the home, while a bit chaotic at times, seem to be normal. Bobby has stepped not only into his teen years with normal excitement, but also seemingly has stepped up to the role of lead male in the home.

Bobby was born April 8, 1999, in Lynchburg, Virginia to Mandy and James S. Bobby had a very close relationship with his maternal, wheelchaired, grandfather until his death in 2009. He "worshipped the ground he walked on" (Bobby, interview) due to his love for the outdoors, cars, trucks, guns, and specifically his grandfather's love for him. Bobby has a very warm place in his heart for him.

Cognitively, he struggles with the use of his cognitive skills. While he can fully communicate at an adult level, he appears to be stuck in self-consciousness and self-directedness stating that "things got a bit murky when dad got sick" (Bobby, 2016). He can communicate through historical events with clarity, remembers family history, events (both good and bad), impact of deaths in the family, and expresses understanding of reactions and disturbances within the family. Bobby understands the concepts of action and consequences, resolve and restitution, discipline and responsibility. In this, he also is the normal young teen that rebels, fights back verbally, and gets frustrated when misunderstood, yet in the end is willing to accept either resulting discipline or guidance. Bobby appears to be stuck emotionally since his father became ill. His ability to express emotions is stoic, mechanical and lacks the ability to

communicate the pain he is experiencing in his father illness. His self-consciousness becoming more of a self-survival and a screaming voice within him to be heard and understood. His father's illness has rocked this young man's world.

Emotionally, Bobby is a paradox, he portrays the mind of a young man, wise before his time, understanding of circumstance, and while deeply sad over his father's illness, Bobby perceives that his father may not be around for many more years. He is very aware of this reality yet is unaware of his loss of childhood along the way. He knows his weaknesses and accepts his failings, at least verbally. He compensates for his shortfalls socially, but his extensive bodily exercise routine compensates. He portrays a strong self-esteem, physically larger than his age group, and accepts and celebrates his family heritage as deep and rich. He is devoted to his immediate family and the needs of the home, and rarely has more than one friend at a time. He has an exceptional work ethic and is known all over town for his landscapes business he runs during the summer.

***Beck Depression Inventory (BDI).*** Bobby revealed much of his heart in counseling including features that can be best described by symptoms of a depressed mood. Based upon these revelations, I felt it important to evaluate his depressed mood using the Beck Depression Inventory (BDI). With his permission, the following results were made clear. There are three important features affecting depression in a person's life. Bobby has significant history of loss, rising negative feelings towards self, his fathers recently diagnosed MS, and significant family history of trauma, disease, and abuse. Bobby scored in the high percentile (30) on this inventory and falls within the moderate

depression criteria. His mood swings, lack of sleep, anxiety, depressed moods are all indicative of these scores (Beck, 1961).

Bobby met three of the major criteria for situational depression: negative feelings towards oneself, negative feeling arising from repeated failure or inability to do well in various aspects of life, and negative feelings due to his father's mental illness (American Psychiatric Association, 2013).

Bobby admitted to having "down" days, but he denied any formulation of suicidal behavior or plan. His delinquency was gaining strength at school as he missed 60-70 % of all his classes in 2015. His desire to stretch his wings, and fly was becoming stronger every day I met with him. Depression had invaded his thinking, his soul, and vision for life. Loss of sleep, difficulty in concentration, and periods of daydreaming filled his days. The reality of his father's condition had created incredible loss of hope for the future in this young man. His role as "lead" male in the home was overwhelming as well as beyond his ability. He is in counseling for this inner battle at his request.

It is in the world of Bobby's moral development that he excelled. Bobby's influencers had predominately centered on three areas of his life, religion or the church, family systems, and historically, his relationship with his grandfather. Religiously, Bobby never missed an opportunity to excel in the church setting He was a regular attender, consistent volunteer, had a "get er' done" [The name of his lawn mowing enterprise] mentality and a faith that showed up in his actions, not just his words. He is an avid reader of the Bible, attended youth ministry Bible studies and small groups, had a

relationship with the youth pastor, and saw himself in a “blue-collar leadership” ministry in his adult life.

***Impressions and concerns – Bobby.*** Bobby scored in the high percentile of the Beck Depression Inventory and while he denied any suicidal/homicidal ideation, situational depression is a deep reality in this young man’s life. Bobby’s family history is chaotic at best. These results represent a common denominator for youth who tend to shut down both emotional and verbally. Bobby’s emotional development has taken major hits along the road. He is a good kid with aspirations of a successful and full life. How Bobby handles the next years of his life, under the umbrella of his father’s illness, will be best handled under the watch care of clinical therapy.

It is important to note, that because of these initial interviews and assessments with Bobby that this family became the primary interest for this thesis. His entire family is given permission for this research on their behalf. Bobby’s sister, Bobbie, is the next child of three.

**The children: Bobbie.** Bobby’s sister, Bobbie, is a healthy, and normal teenage girl in every way. She loves boys, is hopelessly addicted to texting and her laptop, and has incorporated into her life a healthy group of friends. In our conversations, both in the summer of 2016, and more recently in December, Bobbie was very quiet and reserved, a young lady of few words. Much of our communication was in her non-verbal communication style. She teared up easily, fidgeted with her hands, and her eyes focused on a distant spot on the wall. Bobbie seemed lost in the midst of not only her father’s illness, but also in her place within the home.

When asked if she loved her parents, she simply nodded yes, but verbally spoke of her relationship with her brothers Bobby and Tommy as “pains in the ass”. She was not given any assessments due to non-availability throughout each of the visits in the past 2 plus years, and the two conversations she could attend, were short and simple. While she was not available for individual meetings, she did attend the several family meetings with me throughout the last year. Most of the time, the words, both verbally and non-verbally were poignant and to the point. It is as if this young lady was screaming within, “Get me out of this place”. During family sessions, Bobbie was normally very quiet and sullen, usually busy on her phone at the displeasure of her mother, Mandy. As will be explained later in this chapter, the use of psychoeducation, prompted many questions by Bobbie, to the surprise of all members of family.

**The children: Tommy.** Tommy, the youngest of the three is 7 years old. He is all boy, wild, rambunctious, diagnosed with ADHD by a family physician, and is simply a delight to have converse with. In conversation, he seemed to be unaware of the disease enveloping his father, but verbalized a change in the home. “We don’t have as much fun anymore since daddy lost his job” (Tommy, 2014) he shared, showing he didn’t know about the illness. “We don’t get much for Christmas either” he shared in an interview two weeks before Christmas of 2016. Tommy is on an island of his own, playing by himself, alone in his thoughts, yet sensed the ominous presence of “something” that has unsettled the home. Developmentally, Tommy has a good memory and hand eye coordination, pays attention to details, even though a bit scattered by his ADHD, and could identify colors, parts of his body, tastes, smells, and is very aware of his own body



changes as he grows up. He is frequently found playing alone, which he does well, with his vast number of toys scattered about his room. James and Mandy have tried to communicate the severity of James's disease to Tommy, but they are met with his apparent inability to comprehend. Later in this chapter, are recommendations made to James and Mandy to better communicate James' illness to Tommy.

There are four questions that form an implementation plan for James and Mandy's family: How has MS effected the family, what collision points are pivotal in the formation of healthy outcome plan, how do both EFT and NT, benefit the family coping with MS and finally what positive results occurred?

### **How has MS Effected the Family?**

First and foremost, James struggled with his diagnosis of MS in 2013, and to say it affected his life is an understatement. Why anyone in his middle 30's would be affected is still unknown. National MS Society has defined the primary demographic of early onset MS to those in their early 30's (NMSS, 2017). James fits this demographic: The cause of MS is still unknown – scientists believe the disease is triggered by an as-yet-unidentified environmental factor in a person who is genetically predisposed to respond. The progress, severity, and specific symptoms of MS, in any one person cannot yet be predicted. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease (NMSS, 2017). James combats and struggles daily with these symptoms:

Within the central immune system, the immune system attacks myelin — the fatty substance that surrounds and insulates the nerve fibers — as well as the

nerve fibers themselves. The damaged myelin forms scar tissue (sclerosis), which gives the disease its name. When any part of the myelin sheath or nerve fiber is, damaged or destroyed, nerve impulses traveling to and from the brain and spinal cord are distorted or interrupted, producing a wide variety of symptoms. The disease is thought to be triggered in a genetically susceptible individual by a combination of one or more environmental factors. People with MS typically experience one of four disease courses, which can be mild, moderate or severe. (NMSS, 2017, p. 1)

The effect of the MS on James and Mandy has been catastrophic. The challenge of “role swapping” or reversal of the bread-winning role, ongoing arguments, frustrations, disappointment, unmet expectations, financial strain, personality change in James, family role changes and general neglect of Mandy’s own physical and emotional symptoms and illnesses. Secondary or surrogate trauma, in that it was a surprise on the family, has been significant. Johnson elaborates further on the idea of trauma, “Separation from attachment figures can be conceptualized as a traumatic stressor that primes automatic fight, flight, and freeze responses. Aggressive responses in relationships have been linked to attachment panic, in which partners regulate their insecurity by becoming controlling and abusive to their partner” (Johnson, 2008, p. 114).

James’s symptoms are not simply physical, but also mental and psychiatric symptoms of this disease are present. As stated earlier in this paper, James is hampered in life by both depressive moods and anxiety associated with adjustment to his physical disease. “Persons with MS appear to have a higher prevalence of a number of

psychiatric symptoms and disorders, Depression and anxiety, in particular, have been associated with decreased adherence to treatment [3], functional status [4], and quality of life” (Chwastiak, 2009, para. 1).

As a couple, James and Mandy are alike in that they both can be contrary, they question situations and reality resulting in growth, oppose authority which leads to a more careful examination of life both physically and emotionally, and they differ and can be reckless (financial struggles) and have periods of doubt though their faith in God draws them close to reality daily (Mandy, 2016).

James and Mandy’s collision in relationship has resulted in challenge, crisis, and fear. It is here the faith they share resonates from them both, in the middle of crisis. This collision of personality cannot overlook the tenacity and strength they have both found in their God. Their personal faith, the church surrounding them with hope and love, and their friends (many people of faith) continue to walk with them and remain the foundation for their strength. Their theme is one of courage, one of hope, and one of a tenacious spirit. One can only hope and dream of these characteristics in one’s own life.

How have the children been affected? Bobby, Bobbie and Tommy have, in their own way weathered the storm. They each acquired new battles to face through the years of their lives. The prospect of possible exacerbation of James’s illness looms on the horizon, the accompanying depression in each of its forms has invaded the household. Like her mom, distancing has become the modality of choice for Bobbie. Bobby has assumed a leadership role, meant more for an adult, and will one day face

the loss of his adolescence due to the terrible illness his father battles. Alongside this difficult road. Tommy will remain aloof until age allows him the understanding and attachment allows the resonance with his parents, bringing to him the emotion that accompanies the valley of depression, dad walks in.

Other effects include such as job loss, grief, parenting, finances, intimacy and loss of companionship, and communication have all been direct effects of this devastating disease visited upon James.

### **What Collision Points Are Pivotal to a Healthy Outcome?**

Perhaps there is no other area in James and Mandy's life so important as in the areas in which they collide or the backdrop of the present issues in this family. Metaphorically, these backdrops serve as magnifiers of the present crisis. I am convinced that whenever two people come together in a marriage bond that a collision occurs, a collision of personality, faith, histories, culture, trauma. and crisis, as well as family heritage and rules.

As a couple. James and Mandy have long histories of abuse (Genogram, Illus. 1), neglect, abandonment, medical crises (cancer and kidney failure), mental and psychological issues (bi-polar, depression, suicide, ADHD, and alcohol/drug dependency addiction). Through it all, they stand strong, side by side, facing the giant (in this case James's MS). They raised three children, which while having their own struggles with dad's illness, are succeeding in life. These collisions point's in James and Mandy's life cannot be overlooked when approaching the emotional and mental health needs in therapy.

## **How has EFT/NT Benefited the Family?**

In the ongoing evaluation and assessment of James and Mandy's marriage and family, the use of Emotion-Focused Therapy, with understanding of attachment theory and Narrative Therapy, has been predominant. EFT is defined by Johnson as, "In couple therapy emotional signals are the music of the couple's dance" (Johnson, S.H., 2008, p. 108). While working with this family, this "dance" was paramount that a relationship be established and a journey enjoined, to move each member away from the negativity and rigidity to a place of flexibility and sensitivity, and the trust to confront the elephant in the room. It was important to allow this family to expand their experience and interaction, allowing for access and reprocessing of circumstances, and to create new interactional events. When this works, each partner and member of the family unit becomes a source of security, protection, and contact comfort for each other. The role of the therapist or counselor is simply to be the choreographer, process consultant, and, the one who guides the couple and family towards restructuring (Johnson, 2007, p. 14-18).

In James and Mandy's family, it was important, throughout the 8-10 individual session and the 6 family sessions to establish clear goals, via the EFT process, to not only assess but to see clear success' along the journey. My goals were:

1. Come alongside this couple and family to aid them in securing their broken attachment needs and write a new narrative of the bond between James and Mandy and the children.

2. Come alongside this couple and family and aid in choreographing new cycles through new vulnerability.
3. Come alongside this couple and family and help them in speaking to their attachment injuries.

In securing their broken attachment needs, James and Mandy's home needed to be restructured and new understandings had to be formed allowing history to be grieved so they could focus on the "here-and-now" that needed to be addressed. This new narrative, following sessions allowing for forgiveness, became a foundation for the story to follow. The illness and accompanying mental struggles had caused a gulf between Mandy and James, as well as the children. The attachment of a relationship and that of a parent has been severed and chaos ensued. Through EFT, in couple sessions and family group settings, empathetic listening, attendance to emotional needs, expressions of heart were highly attended to. James was many times unaware of the emotional needs of his wife and his children.

Using a model formulated through the Preparation Relationship and Enhancement Program (Markman, H., Stanley, S., & Blumberg, S., 2010), I aided James and Mandy to connect through the concept of speaker-listener technique. Following several attempts for both to begin the process of paraphrasing one another's words, they begin to hear and feel and resonate one another's feelings and pain. I used this process several times in family settings when the children, especially Bobbie, was not understanding or choosing to ignore communication during our session. When she

comprehended the injury, and was able to articulate her own injuries through her father's illness, emotions were freed to be expressed.

EFT speaks to attendant injuries (Johnson, S. M. 2008, pp. 107-110, 122). EFT allows for articulation of the impact of injury, articulates the levels of grief (in this case multiple levels by all family members), and aids in articulating James responsibility and his personal acknowledgement of his illness and impact on the family. The use of EFT in individual and family counseling articulated the need for comfort by injury family members, as seen the almost family wide stoic approach to emotions surrounding James' illness. Once emotions and feelings were elevated and acknowledged by family and James, growth was evident. Growth is defined through EFT as the need for a new narrative of the event.

While they continue their family journey and individual journeys, this new focus on the present must be maintained for healthy growth. In the telling of their "story", the narrative (White, 2015) was allowed, honored, listened to, and reflected upon as the family began to gel and come together in a new sense of vulnerability.

When this family first came together to deal with the issue of MS and its accompanying depression, attachment needs were challenged and stretched, yet not broken. Bobby, in all his mixed emotion of being 15 years old remained secure in his attachment to mom and dad, and only strengthened that bond over the following years. Bobbie, the lost child during the crisis, showed signs of an anxious avoidant, feeling separation anxiety, and has not always felt reassured in mom and dad's presence. She will remain the wild card in the future and how she plays out her life in the years to

come is still to be seen. Tommy remains his fun, active, secure, and ambivalent self during the firestorm of both the health crisis and mental illness.

Mandy, Bobby, Bobbie, and Tommy have all become caregivers, whether invited to be or not, they have taken on the role in the home. In acknowledging this reality, each will face their own level of stress and emotion. Their father and husband is no longer the man he once was in their lives. Broken, tired, depleted, and depressed, James awakens each morning with the new reality of the man he is now.

The application of both Emotional Focused Therapy with Attachment Theory and Narrative theory served well in the formation of a therapeutic relationship for a family with both physical illness and mental health challenges.

### **What Positive Results Occurred?**

In these final pages, I will delineate a plan to reduce both the extreme levels of anxiety and stress residing in James and Mandy family, and provide a step-by-step approach for the reduction of emotional and compassion fatigue, experienced directly, resulting from caring for James in both his physical and mental illness. Overall, the cohesive structure of the family lies in their personal faith in God. Their commitment to their belief system is the glue that holds this fragile family together. The Biblical concept of home is extremely important to each member as well as commitment to church, commitment to personal faith, and an understanding of God's overall plan in their lives. This provides the peace needed during this storm.



**Emotion and Stress.** “There are 4 types of people in this world: Those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregiving” Rosalyn Carter (Feuerstein, 2009, para. 1),

The levels of emotion and stress in a home, like James and Mandy’s, since the diagnosis of his disease four years ago, exacted a toll that no instrument can accurately assess. Nights filled with fear, tears and sadness have not only been a regular part of James’s life, but also of his family. The process of EFT and Narrative Therapy allowed this family the opportunity to finally take in the resources needed to weather the storm.

Facing the ups and downs of daily life do not have to be days of gloom and despair. Thankfully, there have been thousands of others who made this journey and journaled their stories. Thanks to organizations like the National MS Society, one can research, understand, and come together with others experiencing similar circumstances and choose to live life better. The National MS Society rallied around James and Mandy’s family and came alongside to be a beacon of educational hope for all of them. Along with this support, however, the reality of daily emotional and physical triggers abounds.

Observations of this family has led to a conclusion that there are three emotional/physical triggers that scream, “I am in over my head!” From these triggers, there is hope and understanding for the days ahead. James and Mandy and their family, are not alone. However, realization begins by one word, recognition. Recognition is coming to the realization in one’s life that he or she is truly in over his or her head. With this recognition comes the first steps to healthy living.

First, James and Mandy have recognized the potential for loss of identity in caregiving. “Usually OUR sense of being derives from our identity with the world, and therefore the loss of identity carries with it the feeling of loss of being, of death” (Nelson and Nelson, eds, 1996). Washburn added that this recognition of loss of identity focuses on a dying to the world, an alienation from established patterns and of expectations, and a self-consigned to “limbo”. Former identification no longer has a home, your meaning is cast out with memorabilia, spectators of our lives... seemingly hopeless, and yearning for something not yet known, all of which invades not only the afflicted, like James, but the entire family. James and Mandy and family have gone through a complete family make-over, their personal and family identity has changed as seen in their specific descriptions (p. 191-197).

Second, James and Mandy have recognized loss of partnership since the disease and the caring for it doesn’t simply affect their life, but it becomes their life. Outside activities disappeared, friends distanced themselves, and in many ways, the disease became a limbo place for all involved.

Third, James and Mandy recognized the loss of home. The definition of home became redefined and shaken as roles change, and expectations were being renegotiated.

It is both human nature and the nature of caregiving to feel that we alone must tend to all our spouse’s needs, always. Holding to that belief is a cause of inestimable stress, letting go of it is the “window of coping. The caregiver wants to remain in the fairytale, this catastrophic illness forces us to leave behind the

make believe. ...it is a patient heart that releases suffering, for it is not who we are when caregiving begins that defines our character and sets us free, but who we end up becoming. (Rouche, 2000)

The loss of identity, partnership, and home have taken a toll on the family, relationship and life. There are innumerable anecdotal thoughts shared about loss in circumstances much like James and Mandy's family. Caregivers across the United States rally through caregiving sites such as; National Council on Aging, American Association Retired People, National MS Society, International MS Society, National Family Caregivers Association, Caregiving: The Spiritual Journey of Love, Loss and Renewal, Caring for Your Parents: The Complete AARP Guide. They all provide needed information in recognition of the losses suffered from the invasion of this illness into the home.

From these sites encouragement and understanding abound. As one caregiver said... "I'm different. Sometimes I am not sure who I really am." Others experience many types of loss, including loss of relationships and social or recreational interaction with friends, spouse, coworkers, and children persistent feelings of isolation, roles, identity, and sometimes occupation as the role of caregiver continue, control over personal time, freedom, privacy, future, and life events well-being, including emotions, such as worry and guilt feelings, concentration, and health issues, such as lack of sleep and diminished physical capacity.

Identifying these losses have become the first step toward understanding these feelings. There are also losses that are not easily identified. Although the care-receiver may be physically present, he may be mentally or emotionally absent. He may not be

quite the same person that he used to be. These ambiguous losses can trigger complicated reactions with no rituals to guide them through the grief.

Before identifying eight proven steps in beginning the process of digging out in chapter five of this project, an important diversion needs to take place. As has been noted in both Emotional-Focused Therapy and Narrative Therapy, there remains the need for story to be told. It is extremely important in this family that communication in all forms be not only education but also practiced. Of the many interviews and family sessions I shared with this family, the strongest sense of breakthrough came in my last family session. In this session, Bobbie was heard for the first time as she shared her loss of her mother throughout this journey, her pain of being alone, her need for connection, and her need of her father... the tears flowed as she shared openly for the entire family to hear. Steps were taken to ensure the bond she once had with her mother and father would be addressed and strengthened once again. Bobby was given verbal permission to let go of the leadership role of the home and to celebrate his last year of high school as a teenager. Mandy acknowledged her need to not fear the home and the potential loss of her husband, and while not immanent, the possibility of James's loss lay at the root of her belief system.

James continues to struggle with his health, battles periods of depression and anxiety due to the "invisible effects" of the disease, and works hard at modeling the portrait of a father and husband of faith before his wife and kids. He remains in Christian counseling, as a positive step in achieving this goal in his life.

It is here, in the midst of the storm, that this family, and the individual is challenged to reconsider his or her faith. The storm is real, the waves are high, the pains and aches seem insurmountable, the days are long, and hope is dashed. This therapist has heard to many times the question, “Where is God now?” from those losing a marriage, buried in debt, child out of control and in James and Mandy’s life, “why me?” (James, communication) In chapter five, I will present the resultant workshop from this project, and in this case, presenting specific steps to weathering the storm if chronic illness in the home. Perhaps, the unknown author of this following poem has it right, “faith sees her God through the eye of the storm”.

#### **THE EYE OF THE STORM**

Fear not that the whirlwind shall carry thee hence,  
Nor wait for its onslaught in breathless suspense,  
Nor shrink from the whips of the terrible hail,  
But pass through the edge to the heart of the gale,  
For there is a shelter, sunlighted and warm,  
And Faith sees her God through the eye of the storm.  
The passionate tempest with rush and wild roar  
And threatenings of evil may beat on the shore,  
The waves may be mountains, the fields battle plains,  
And the earth be immersed in a deluge of rains,  
Yet, the soul, stayed on God, may sing bravely its psalm,

For the heart of the storm is the center of calm.  
Let hope be not quenched in the blackness of night,  
Though the cyclone awhile may have blotted the light,  
For behind the great darkness the stars ever shine,  
And the light of God's heavens, His love shall make thine,  
Let no gloom dim thine eyes, but uplift them on high  
To the face of thy God and the blue of His sky.  
The storm is thy shelter from danger and sin,  
And God Himself takes thee for safety within;  
The tempest with Him passeth into deep calm,  
And the roar of the winds is the sound of a psalm.  
Be glad and serene when the tempest clouds form;  
God smiles on His child in the eye of the Storm.

(Cowman L. B., April 23, 2006)

## **CHAPTER FIVE**

### **RESULTS AND WORKSHOP PROJECT**

This workshop was designed, first, to reach a specific target audience of those families struggling with the impact of chronic illness in the home. Second, it sought to reach those struggling with effect of mental illness, a result of chronic illness in the home. Finally, this workshop takes specific recommended steps to encourage both demographic communities with the steps to cope and find hope throughout their circumstances.

Accompanying this chapter is an addendum PowerPoint, designed to accompany and support this workshop. The workshop is designed to be either two-hours or five-hours in length, targeting a group of no more than 35 individuals, to provide intimacy and openness of sharing, and held in a non-threatening environment.

On the final page of this chapter, I will provide an hour to hour breakdown on the workshop in whole. Using that breakdown and outline, the following discussions and education will serve as the content of the outline. Four separate sessions, an hour and 15 minutes in each, and teaching, discussion and reflection, will be offered.

The length of the seminar is important to these two communities as they each come with their own considerations and limitations. For example, time out of the home is an issue, due to the need of the caregiver to be at their loved one's side. Providing care for a loved one, suffering from Alzheimer's, a type of dementia that causes problems with memory, thinking, and behavior creates barriers to find four hours away to attend a workshop. In addition, care is given for the attendee with the chronic illness

and allow him or her time throughout each session to ask open questions if the need arises. Dividing the workshop into four specific, standalone topics provides an opportunity for attendees to attend a few hours at a time. In addition, ample notes and video copies of the workshop will be made available to ensure cohesive understanding of the presentation, should their departure cause them to miss anything. The size of the group is extremely important as the content requires an atmosphere of intimacy, and an atmosphere of congeniality. While confidentiality cannot be promised, it will be highly encouraged to enable open sharing by all attendees. Intimacy lies at the very core of the need for each of the two communities being served. The lack of intimacy, or tenderness, closeness, or companionship remains a hidden cry of the clients this workshop desires to address.

The workshop will be held in an atmosphere or location that feels warm, secure and safe, to provide the attendees of chronic and mental illness a respite from their chaotic life. When an attendee is moved to tears, he or she must know the location will not interfere with the expression of feelings.

### **Objectives**

In this chapter, I describe my hope for the workshop, and delineate four specific goals and expectations for the attendee to find in his or her life:

1. It is my hope attendees are recognized and encouraged in their individual and familial journey. I believe people with chronic illness have needs that currently are not being met by traditional “resource-centered” education.



2. It is my hope that in these few hours spent together, educationally, attendees can take home two to three principles, lightening the load of their circumstances. Example would be permission given to express anger in a healthy setting.
3. It is my hope this day will activate taking courageous steps for attendees in forming an alliance with someone there. An ally to reach out to in those dark hours provides a listening ear to restore hope.
4. It is my hope that they can partner together so attendees touch people just like themselves. They benefit from allies who understand what it is to feel trapped, immersed, discouraged, depressed, angry and simply put, lost in the woods thinking no one else is there. Different from the third objective in that this seeks outreach over that of in reach. To discover together the community around them, through associations, workshops, drop-in centers, retreats as well as church.

### **Implementing the Vision**

In the pages, ahead, I spell out the emotional and physical triggers among caregivers in the homes of the chronically ill. I will define the concept and causes of compassion fatigue on the family of the chronically ill. Finally, I will reiterate (chapter four) eight action steps that can aid in the process of digging out, or getting the attendees' feet back on the ground.

**Session One: Recognizing the Issue.** While there are many chronic illnesses in this world, I use two specific illnesses to illustrate the concepts of this workshop. The world of those suffering from MS is vast, and the specific example of James and Mandy, and family provide a backdrop for illustrating the principles learned. Against the backdrop of James's MS is a second chronic illness that runs parallel. The world of Alzheimer's disease has affected countless 1.3 million across the world and in many ways, the effect on the home is similar.

Secondary to the hopes of this workshop will be to give attention to the growing concern for caregivers, often family members who sacrifice their lives, give up careers, are on the front line of their loved one's disease. In the case study researched, care was given to recognize the plight of Mandy and the kids in their journey with James.

#### Multiple Sclerosis

In this workshop, the research and facts about MS will be shared at length. MS is here to stay, and the devastating effect on family is real. For Mandy and the kids, life will not change. There will be seasons of respite resulting from the remitting/relapsing form of James's disease, but it will not go away.

*Alzheimer's disease.* Johns Hopkins Medicine is closing the gap in its understanding of Alzheimer's disease. "With our population aging and the numbers of Alzheimer's disease patients in this country predicted to steadily increase over the next two decades from 5.5 million today, the number of caregivers must increase as well." (Hopkins, 2017) Their message warns people they will likely be providing care to someone with this disease at some point in their future.

Being a caregiver for a family member or friend with Alzheimer's disease can be so stressful that doctors often think of caregivers as "hidden patients". Because caregivers are often faced with overwhelming day-to-day responsibilities, many stop going in for medical checkups, self-medicate anxieties with alcohol, do not exercise, and eat poorly (Hopkins, 2007).

It is clear, in these brief statements about MS and Alzheimer's disease, the future is bleak for the caregiver or family member of either disease. Chronic illness does affect the family. On a side note, take a few moments and envision the future through the eyes of the future needs in healthcare. These examples are but a portion of the facts available in the caring for and providing for the ill in our future.

An estimated 43 percent of Americans age 65 or older will spend time in a nursing home (New England Journal of Medicine, 1997).

By 2012, 75 percent of Americans over the age of 65 will require long-term care. Nursing home costs are high, between \$40,000 to \$70,000 per year, depending on where you live. The average length of stay in nursing home is 2.5 years (TMS, 1997).

Long-term care costs are rising at 6 percent annually (Fortune, 1996).

73 percent of Americans incorrectly believe Medicare is the primary funding source for most older persons' long-term costs (American College of CLU, 1996).

In 1999, it was reported over 25 million Americans provided 80% of the home care to ailing or vulnerable family members. (New fact states that number will change to over 80 million (boomers) (NCOA, 1997).

In 2000, a survey found that 26.6% of the adult population provided care for the elderly, disabled, or chronically ill, friend or relative, which translates to more than 54 million people. And, 37 percent of caregivers are living in same household as the person they care for, while 54 percent of caregivers are between 35 and 64 years old.

In isolating the idea of caregiving, Roche (2009) wrote of the importance of premium caregiving in the future. Premium caregiving is pivotal to achieve quality care for persons with chronic or disabling conditions. Unpaid informal caregivers currently provide for a substantial proportion of care recipient needs including 80% of long-term care needs in the United States. Within the next 2 decades, 78 million baby boomers will reach 65 years of age and older, creating unique and extensive challenges to an already flawed health care system; this older cohort will at minimum increase utilization of health care resources” (p. 200).

At this point in the workshop, a breakout session will occur. Groups of no more than 8, will gather for a 15-minute period and discuss the following question: “What emotional and physical triggers do you experience daily in the care of your loved one?” A breakout session will occur each hour and is a direct application of the understanding of Narrative Therapy, or that of telling your story. It is in the hearing of other’s story where normalization and understanding begins to grow. It is in the story where the feelings of being alone begin to lighten. As the emotions are shared and are resonated with by other participants, the attendee feels heard and understood, perhaps, for the first time in their lives. The importance of flexibility and allowing for ample time is important to the emotional goal of this exercise.

**Session Two: Emotional and Physical Triggers.** The Johns Hopkins Medicine has spelled out ten specific emotional and physical triggers that invade the life of the caregiver, displayed by Mandy and the kids. In the world of MS, many of these triggers lie dormant and hidden, only to rise when the intensity of the disease grows, and the potential of death might heighten. While the Johns Hopkins Medicine are specifically targeting the Alzheimer's disease in this article, the content can transfer to the corresponding triggers in the MS world (Hopkins, 2017, para. 1).

Denial is first of the ten triggers, just as it is the first step when facing grief. Kubler-Ross & Kessler (2014), define each stage in *On Grief and Grieving*: The stages are: denial, anger, bargaining, depression, and acceptance. Denial whispers in the mind that this disease isn't happening, doesn't exist and with MS, challenges the hiddenness of the disease. As discovered, MS is many times the disease without definition and remains hidden to the eye, unlike its physical characteristics that become visible in the advanced forms of MS. The outward appearance of MS, especially when accompanied by emotional/mental health issues, is difficult to cope with by family, as it does not bare the physical characteristics (pp.4-6).

Anger is the second trigger, and another facet of grief (Kubler-Ross et al, 2014). It is the statement, "If he asks me that question once more, I will scream...". The emotions that bubble under the skin, create a need to vent which often happens when confronted. Anger is the emotional reality and heightens, when hope is dashed.

Third, withdrawing socially occurs when one no longer wants to stay in touch with friends, or participate in activities once enjoyed. It is here the therapist takes

serious note. This withdrawal is one of several indicators of the presence of depression. The feelings associated with depression, occurring at this point turn inward, want to hide, want to ignore the reality of the life now occurring. Mandy shared she finds that withdrawal is impossible in a home of three children, yet finds her employment, ironically, as a place to withdraw to (Mandy, 2016). What is intriguing about this reality is she works as a church secretary, meeting the emotional and physical needs of parishioners daily. The act of withdrawing socially communicates the feeling, “I don’t care about getting together with the neighbors anymore” (Hopkins et al., 2017).

Fourth, anxiety is worry on steroids. It is the fear of the future and the hopelessness behind depression. Anxiety wonders who will be there for my loved one if I can no longer provide care. It is the reality when others in the family need my support and dad needs all my attention. Anxiety is what keeps me awake, when all else seems okay. Anxiety, out of control has the potential to become a mental illness. Anxiety left alone becomes despair.

Despair is feeling sad and hopeless much of the time, and as the fifth trigger, it screams within, “I don’t care anymore” (Hopkins, 2014). Bobby, Bobbie, and Tommy shared that they felt this many times. In the ups and downs of James’s illness, when relapse turns to remitting or the MS takes a turn, hope is raised only to be dashed by relapse. Bobby shared it is then, he turns within, despair rears its head, and unhealthy thoughts overtake him (Bobby, 2016). Bobby describes this journey as exhausting.

Sixth, exhaustion is barely having the energy to complete daily tasks (Hopkins, 2014). It is the expression heard in every support group meeting, “I do not have the

energy to do anything anymore.” It is the patient exhausted, who is always looking for the bed to crawl into, the couch to curl up on, and the day to be over. He or she wants sleep, yet struggles to find it, even in bed.

Sleeplessness, a seventh stage, is uncommon among the caregiver’s world. The caregiver or family member becomes hyper-vigilant to noise, sounds, and cries of their loved one. Mandy speaks of not having slept for years, and when sleep does arrive, she is startled awake by nightmares, stressful dreams, or fears of James’s demise to the MS disease that plagues him (Mandy, 2016).

In this eighth stage, guilt cannot give enough, feels bad they feel that way, feels sorry for self, feels hopeless. In ongoing interviews with Mandy, she often speaks of the guilt that has become a part of her normal mental process. “I am alive and well... this is so unfair to James” (Mandy, 2016). There is nothing the caregiver can do, and a feeling of being lost, pain, and hate to become a part of the language. As if human, guilt drives in deep, sets up camp, feeds on the belief system and violates the health of its attachment (Hopkins, 2014).

Lack of concentration is the ninth of ten emotional triggers, the caregiver shares they cannot focus anymore, discovers it difficult to complete complex tasks, and wonder if they are losing their minds (Hopkins, 2014). Mandy shared of standing in the kitchen, staring out the window with a pile of dishes in front of her, and forgetting where she is. Bobbie shared the increase of day-dreaming while at school. The mind unattended to can drive the body to react.

Finally, health problems, loss of weight, colds, flu, chronic backaches, headaches, high blood pressure, acne, diarrhea, skin issues, stomach aches, Crohns disease, and many more health-related issues become a reality in the loved one dealing with chronic illness. Many caregivers, throughout caregiving groups either online or in person, also complain of colds that will not go away, and headaches that stay, even though medicated. The body under stress is an oasis with illness is waiting to invade.

Health problems raises a flag of concern and brings attention to the fact that the caregiver or loved one is not alone in their plight. They are surrounded in this workshop by people like them, either the afflicted or the caregiver. They are not alone.

***Losses Along the Journey.*** At this point in the workshop I introduce the subject of loss as it pertains to the family member living with chronic illness in the home.

First, like the home of James and Mandy, one must recognize the potential for loss of identity in caregiving. Former identification no longer has a home, your meaning is cast out with memorabilia, spectators of our lives... seemingly hopeless, and yearning for something not yet known, all of which invades not only the afflicted, like James, but the entire family.

Second, as in the relationship of James and Mandy, one must recognize loss of partnership since the disease and the caring for it doesn't simply affect our life, but it becomes our life.

Third, like in the relationship of James and Mandy, one must recognize loss of home. The definition of home becomes redefined, and shaken as roles change, and



expectations are renegotiated. It is both human nature and the nature of caregiving to feel that we alone must tend to all our spouse's needs, always.

The caregiver wants to remain in the fairytale, and like James's MS, this catastrophic illness forces him to leave behind the make believe. "...it is a patient heart that releases suffering, for it is not who we are when caregiving begins that defines our character and sets us free, but who we end up becoming" (Rouche, 2000).

Identifying these losses is the first step toward understanding the grief associated with them. There are also losses that are not easily identified. Although the care-receiver may be physically present, he or she may be mentally or emotionally absent. He may not be quite the same person he used to be. These ambiguous losses can trigger complicated reactions with no rituals to guide caregivers through the grief.

**Session three: Compassion fatigue.** Figley (1997) defined "Compassion Fatigue [as] the emotional residue of exposure to working with the suffering, particularly those suffering from the consequences of traumatic events." Also, he stated, "professionals who work with people, particularly people who are suffering, must contend with not only the normal stress or dissatisfaction of work, but also with the emotional and personal feelings for the suffering" (Figley, 2002, pp. 12-14).

There are, four irrefutable causes to compassion fatigue. While there remains a multitude of causes, for this project I have identified four. They are identified as empathy, repetition, transference, and collision.

**Cause #1: Empathy.** Caregiving or living with a loved one with chronic illness is impossible without empathy. The caregiver does not volunteer for it, but certainly is

called into this arena because of this very word. It is empathy that draws us to love unconditionally when all seems hopeless. The World Book dictionary's definition of the word writing an "empathist is: A person maintains rapport with others through empathy. It is the quality or process of entering fully, through imagination, into another's feelings or motives. The etymology is derived from the Greek word "emp'atheia," meaning, "en" = in + "p'athos" = feeling. (World Book, 2017, electronic)

Rothchild (2006), wrote,

As caregivers [loved ones, *mine*], empathy is our major, greatest, and most reliable tool. Often it is our capacity for empathy that brings us to the helping professions in the first place. Empathy allows us to relate to others in our care and to have a sense of what they are feeling. It also helps us to put their experiences into perspective, understanding how they are being affected by the incidents that we are trying to mediate. When we have an insight, and accurate hunch, or seem to read the client's mind, that may also be a result of empathy. Without it, we could not be the effective therapists that we are. Empathy is an integral, necessary tool of our work. (para 4)

Speaking to a community of nurses and caregivers, Bradham (2007) stressed a needed balance in the giving of empathy. She shared five, timely, insights for nurses as well as those providing care for loved ones. There are downfalls of empathy in the caregiving world (Bradham, 2007).

1. We can care too much
2. We can confuse empathy with sympathy (pity)

3. We can over extend sympathy where it begins the process of fatigue... simply put we start carrying too much.
4. Our gift can become a yoke (we become manacled/shackled to the emotional needs of both our patient and to our own needs being met through him/her.)
5. Loss of objectivity (depending on the level of empathy applied) Key words: empathy, closeness, bond, emotional distance, apathy, balancing act

The caregiver can give too much, can confuse empathy with sympathy and certainly can over-extend themselves. Bradham (2007) is correct in her assertion that caregiving with empathy takes a toll on the person. When empathy is not paid attention to, certainly what is perceived as a gift becomes a shackle and deed vice a gift to be given.

***Cause #2: Repetition of trauma.*** The world of caregiving is that of, day in and day out, giving of the heart and mind to his or her loved one. Caregiving, even in its simplest form can become tedious and repetitive. "A debilitating weariness brought about by repetitive, empathic response to pain and suffering, compassion fatigue is a result of absorbing and internalizing the emotions of clients and, sometimes, coworkers" explains Debra Hopkins (2013). "It's an occupational hazard that may affect any professional who works day in and day out with those who are physically, mentally, or emotionally challenged, or those who have been traumatized - whether by illness, violence or other tragedies" (Hopkins, 2013, para. 3).

Much like crisis responders or first responders, the caregiver deals daily, hourly with repeated interventions, these alterations can become solidified because the

interventions confirm the validity of the changes in their beliefs. The Department of Justice (2016) published several contributing factors to these changes: First, constant re-exposure to sudden, random crisis, or re-exposure to disaster (crisis) and its consequences is inherent in the role of crisis responders. Re-exposure to trauma triggers the imprinting of traumatic responses in the brain and repeatedly confirms the perception of alarm, danger and its impact. Crisis responders may become hyper alert and vigilant in everyday life.

Second, exposure and re-exposure to the impossible. In many cases of chronic illness, there are little to no solutions, no quick fixes. Like that of crisis responders, a caregiver cannot escape the day in and day out exposure of chronic illness. In many cases, caregiver find one of the most disturbing aspects of their work to be the exposure to "impossible" events. There is no answer to much of what a care provider deals with in chronic illness in the home.

Third, lack of positive countervailing exposure to human good and world order. This is a critical factor. Crisis responders as well as care providers, who can maintain their abilities to function in a positive and healthy way are those who have strong social support; anchor themselves in the knowledge of people who are good; and can sustain themselves with their sense of spiritual connection.

Fourth, lack of nurturing resources. In the life of both the first responder and the caregiver, there remains a very short list of nurturing resources to turn to. In the silence of the night, while one wonders if their loved will awaken the next morning, the tears of the caregiver hoping for another day with her husband or wife or child are present.

***Cause #3: Transference.*** Transference is a phenomenon in psychoanalysis characterized by unconscious redirection of feelings for one person to another. One definition of transference is "the inappropriate repetition in the present of a relationship that was important in a person's childhood" (Webster, 1976, electronic).

Dr. Figley (2002), head of the Psychosocial Stress Research Program at Florida State University, examined the problem in his book *Compassion Fatigue*, he states, "Hearing about past trauma can trigger haunting memories from a therapist's [caregivers] own past" (Figley, 2002). Based on his experience treating mental health professionals, Figley believes the providers more likely to suffer from compassion fatigue are those who are caring and empathetic.

Of the several contributing factors listed above, physical and emotional fatigue are the most prevalent in the caregiver within the home. It is not unusual for caregivers to be both emotionally and physically spent from their efforts. Physical fatigue causes the body to be more susceptible to sensory input. The cognitive functions begin to shut down and emotions surface more quickly in response to what is perceived. Organization of perceptions is more likely to become confused, and perceptions themselves become somewhat blurred and distorted. What may be described as "emotional" fatigue is perhaps more realistically seen as "cognitive" fatigue.

The brain becomes less adept at controlling emotional responses. Thus, when caregivers hear stories about trauma, they are less able to keep their thoughts in order. They may respond to those stories as if the events, reactions, and feelings were

happening to them. They take in the facts more viscerally than they would if their cognitive functions were working normally (Figley, 2002).

***Cause #4: Collision.*** This therapist is convinced that each person possesses a rare blend of gifts, talents, culture, history, passion, vision, and faith that no one else in this world has. Simply put, each has a song or symphony waiting to be played, orchestrated, and displayed.

Each caregiver brings their song to the home daily, they bring their past, present, and future dream. They bring, imprinted in them, their history, culture, drama, crisis, and celebration. They bring their vision for your life, their dreams, their wishes, and ambition. They bring talents, gifts, and abilities, and finally, they bring their concept of God and God's understanding of them. All of this consolidates into the song that is their life. The orchestra of the music being heard...the symphony, their symphony...waiting to be heard. It is in the collision of life with others, the moment of impact that the orchestra begins to warm up, the clash of two, and sometimes many more, begins the interplay of people, and the sounds of music begin. The pains and devastating histories come into one room, memories bring panic, and the invasion of the intruder arrives. It is this moment however, like that of James and Mandy, they find hope in their God, in one another and their children. While sounding a bit like a 60's philosopher, the music begins to play.

So, what is there for the caregiver or family member to turn to during their journey? Where does one turn for answers when there is no answer? With the backdrop of the music, there are steps to be taken, to lighten the load.

**Session four: Eight action steps that can begin the process.** First, it is vital to each family member to be good to their bodies, physically. The importance of good diet, exhaustive exercise, and a little pampering goes a long-way in dealing with the daily onslaught of stress and crisis this family faces. Mandy has lost over 30 pounds in her desire to become healthier, during this journey by simply paying attention to what foods are taken in, and along the journey, even the kids have joined in to support the proper nutrition in their daily eating habits. While there remain the momentary binges and ice cream serves as part of the rite of passage moments, this family is setting a good foundation for a healthy future. Exercise has been a challenge, especially with James's struggle when relapsing; however, this is where Bobby has stepped in to encourage the family of this priority. In the last 3 years, Bobby has gained approximately 30 pounds in muscle mass through vigorous weight lifting. This dedication helped him in several ways. Exercise has helped his self-esteem, when only a couple years ago, he would have avoided team sports for lack of confidence.

Pampering was not a hard sell. Mandy and Bobbie have run with this as if given permission to self-please. Several trips a year to spa days for pedicures and manicures, and of course shopping days have proved to be encouraging. James has even stepped up to the plate and prompted date nights, weekends away alone with Mandy, and his first "mani/pedi" a couple months ago, it is vital to be good to one's body.

Second, it is imperative to lighten your load, through sharing it, through learning to talk about it, and through networking. In several of our encounters together, James and Mandy were encouraged not to hide behind closed doors about James's health. The

church has become a place where they can share, in a non-judgmental setting, the struggles and concerns of MS that face them daily. In counseling, each have the opportunity to talk their “stuff” out instead of stuffing the emotions, leading to future conflicts. Networking has been a challenge due to a fractured MS community in their home area. They found online support for networking, but local support networks fall short of their needs.

Third, it is important to know when to raise your hand and ask for help, and give the pros a chance to step into your life and walk with you through your challenge. Whether it is a local pastor lending his listening ear or in the confines of a confidential counseling setting with a therapist, it is time to allow the input of other’s in your life. James and Mandy have a strong pastoral presence in their lives through church and their pastor. They are encouraged and supported to regularly see a local Christian therapist for both individual and family needs. It is truly okay, from time to time to simply surrender and give the pros a chance.

Fourth, know your body and your emotions. In this project, priority was given to understanding one’s personality and character. When one knows his or her personality type, they know the reactions they are pulled to in crises. A melancholy personality, for example is prone to depression while a sanguine personality might be prone to over commitment. It is important to note how everyone responds to stress, good and bad, to thwart unhealthy responses. Learn to calm your own spirit through breathing exercises, meditation, or prayer, and perhaps even the use of guided time outs. Recent smart



phone applications such as Headspace®, can provide a ten-minute calm, and what the body and emotions needs.

Fifth, American Association Retired People have provided an excellent path to pay attention to with their, “Re-write your inner script” publication (AARP, 2017).

Negative thinking is natural in the stressful life of a caregiver, but it is also a barrier to solving problems and reducing anxiety. Be on the alert for negative responses and try to replace them with more positive statements (Ellis, 1975). The following warnings can change the tone of the home when practiced.

Be aware of Generalizing (words like never, always...)

Be Aware of Ignoring the Positive (the word “but” added to a positive statement negates the effect of the phrase)

Be aware of Jumping to Conclusions

Be aware of Labeling (“I am so selfish, I should be helping more...”) (AARP, 2017, p. 1),

Sixth, tell yourself the truth and understand how truth affects you. Investigate, research, and know the disease well. Through sites like the National MS Society, explore and never accept ambiguity when researching the illness that has taken a center place in the home. Know that many times, research and hope for discovery will fall short of desired goals. This is when a community of like-hearted sojourners is important in the search for answers. It is also important to know your own limitations and to honor them. It is hard enough to even pronounce sclerosis, much less understand all its ramifications in an individual’s and family’s life. James and Mandy have shown courage

to broaden their education and knowledge of both MS and depression to better the family understanding of the disease. For months, MS and depression had truly been the invisible enemies of both the relationship and family in their home. MS and depression do not always have distinctive physical symptoms, no bleeding sores, no distortions to the body, and symptoms many times only known to the afflicted. Through education, they have become knowledgeable, understanding, and supportive, and while difficult at times, the family has bonded together to live with and not against the disease.

Seventh, is the idea of taking a vacation. Using resources found in the first step, take anything from an hour to a week vacation regularly. Learn and practice the “ten minute” vacation using sources such as Headspace, as mentioned earlier. Invest in music to allow the mind diversion and recreation through the vast world of the music and art. As well, taking weekly walks through nature, art, and theater are incredibly helpful.

An idea that has found a following is taking a break away from the afflicted. While often met with guilt and shame, many times in the life of a caregiver, an hour away from the crisis, provides unbelievable respite during the difficult journey. As stated earlier, Mandy and Bobbie have found a few hours away proved to be no longer a possibility but a planned, regular event.

Eighth and finally, invite spirituality into your daily life. James and Mandy are strong proponents of a faith walk. Their belief in God, their daily spiritual mantra has been the glue that held them together as a couple, as well as a foundation for the home. Through reading Scripture, listening to uplifting and encouraging music, prayer, and

meditation, and through both personal and corporate worship, the soul and spirit is enriched and blessed.

### **Summary**

The journey of James and Mandy and family continues, the disease has not let up, the struggles continue, the finances continue to be challenging, hope seems lost at times, the symptoms of depression reared its head from time to time, and the children may push back. Yet, in the midst of this “war”, as Bobby calls it, there have been successes. Hope has been found in one another, church, and God; faith has been celebrated, disability funds were finally granted after three years and several rejections, James and Mandy’s marriage is healthy, and the children, well, they continue to grow.

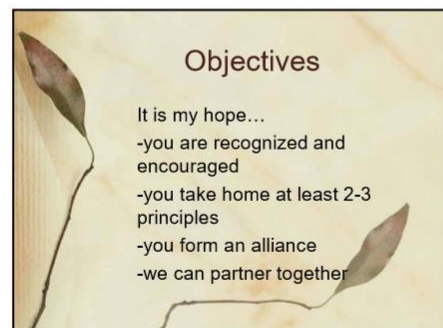
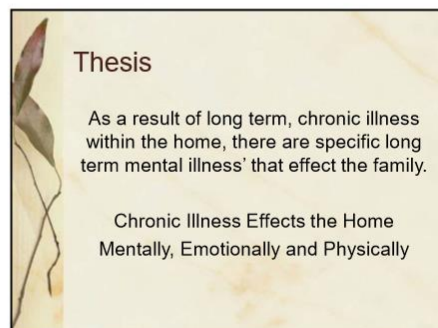
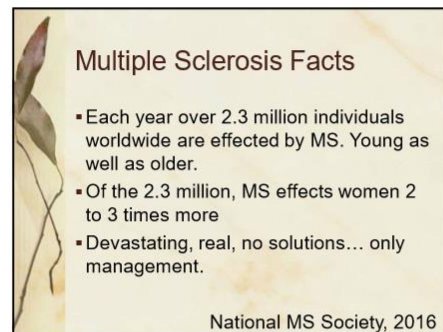
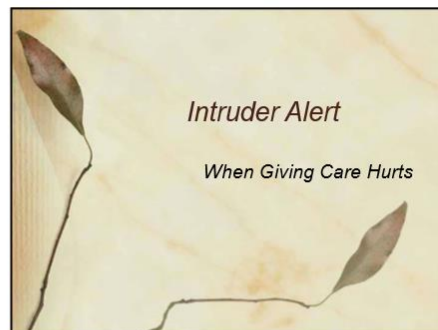
Ann Morrow Lindberg (1991) concludes this project with the thought, “I do not believe that sheer suffering teaches. If suffering alone taught, all the world would be wise, since everyone suffers. To suffering must be added mourning, understanding, patience, love, openness and the willingness to remain vulnerable”


APPENDIX A  
HOME CAREGIVER WORKSHOP AGENDA

**AGENDA: 8:00AM TO 1:00 PM**

<b>Time</b>	<b>Activity</b>	<b>Intention</b>
8:00-8:30	<b>Welcome and Introductions Warm-Up Activities</b>	Logistics Define the audience Goals and Objectives Recognize and encourage Take home 2-3 principles Form an alliance/partnership
8:30-9:15	<b>Session One The Issue at Hand</b>	Intro to Multiple Sclerosis Intro to Alzheimer's Disease
9:15-9:30	<b>Reflection</b>	Step into more reflective dialogue about self and identity in relation to the emotional and physical triggers of chronic illness
9:30-10:15	<b>Session Two Emotional and Physical Triggers Losses</b>	Emotional and Physical Triggers of Chronic Illness Losses along the way
10:15-10:30	<b>Reflection</b>	Identify and reflect together over one loss in the journey of chronic illness, you have experienced.
10:30-10:45	<b>BREAK</b>	During the break take time to get to know four people you have never met before.
10:45-11:30	<b>Session Three Compassion Fatigue</b>	Compassion Fatigue: Causes Causes: Empathy, Repetition, Transference Collision
11:30-11:45	<b>Reflection</b>	What cause stands out in your life in the midst of your journey with chronic illness?
11:45-12:30	<b>Session Four Eights Steps to Digging Out</b>	Digging out Steps to healthy living
12:30	<b>Advancing the Dream</b>	Take time as a group and list five ways to advance the lessons you learned from today's workshop.

## APPENDIX B. POWERPOINT SLIDES





## In the Hours Ahead

Understand the Emotional and  
Physical Triggers and Losses

Define the Concept and Causes of  
Compassion Fatigue

Actualize Proven Action Steps




## Group Discussion

At the end of the day, how would you complete  
the following?


It was a good day because...

It was a bad day because...



*"I do not believe that sheer suffering  
teaches. If suffering alone taught, all  
the world would be wise, since  
everyone suffers. To suffering must  
be added mourning, understanding,  
patience, love, openness, and the  
willingness to remain vulnerable."*

~ Ann Morrow Lindbergh




## Recognition

Session One


- An estimated 43% of Americans age 65  
or older will spend time in a nursing  
home. (NEJM, 1997)

- BY 2012, 75% of Americans over the  
age of 65 will require long-term care



### Recognition

- Nursing home costs are high, between \$40,000 to \$70,000 per year, depending on where you live. The average length of stay in nursing home is 2.5 years. (TMS, 1997)
- Long-term care costs are rising at 6% annually. (Fortune, 1996)



### Recognition

- 73% of Americans incorrectly believe Medicare is the primary funding source for most older persons' long-term costs. (American College of CLU, 1996)
- In 1999, it was reported over 25 million Americans provided 80% of the home care to ailing or vulnerable family members. (New fact states that number will change to over 80 million (boomers) (NCOA, 1997)



### Case Example

*Jason and Menesia...*  
*Married 19 years, 3 children*  
*Eli (17), Ellie (13) and Tobias (7)*  
*Excellent job, great church, strong future*

*Jason's Dx of MS, 4 years ago, loss of job,*  
*chronic fatigue, devastation*



### Case Example

*Menesia...*  
*Role change, from mother and wife to*  
*caregiver, from secondary income to primary*  
*with little to no extensive work hx*  
*Eli, from son to lead male in the home*  
*Ellie, from pre-teen, active and hopeful to teen,*  
*sullen and depressed*  
*Tobias, from active, normal, excited child to*  
*repressed, quiet and lost.*




### Daily Reality

*They all have taken on the role in the home as:*

Caregivers

*They end each day contemplating..  
Was it a good day or a bad day*




### Living the Dream

*In 2000, 26.6% of the adult population provided care... for the elderly, disabled, chronically ill of a friend or relative*

*54 million people caring for others*

Roche, 2009




### Living the Dream

*37% of these caregivers, like Menesia, Eli, Ellie and Tobias are living in the same home of the one being cared for...*

*54% of the caregivers are between 35-64*

Roche, 2009



### Living the Dream

Side Note


*Premium caregiving is pivotal to achieve quality care for persons with chronic or disabling conditions..*

*80% of caregivers are unpaid, informal, and family members...*

*They are people like Menesia, Eli, Ellie and Tobias, You!*

Roche, 2009






**Living the Dream**  
Discussion

*What emotional and physical triggers do you experience daily as you care for your loved one?*

*What is your story?*




**Emotional and Physical Triggers**  
Session Two

*Johns Hopkins Medicine spells out:*

***Specific Emotional and Physical Triggers***

*Invading the life of the Caregiver*

*Johns Hopkins Medicine, 2017*




**Emotional and Physical Triggers**  
Denial

*Denial whispers in the mind that this disease isn't happening, doesn't exist and with Multiple Sclerosis, challenges the hiddenness of this disease.*

*Denial is the first stage of four in the grieving process.*

*Kubler-Ross & Kessler, 2014*




**Emotional and Physical Triggers**  
Anger

*"If they ask the question, one more time, I will scream" (Patient)*

*Anger is the second stage of the grieving process*

*Kubler-Ross & Kessler, 2014*




**Emotional and Physical Triggers**  
Withdrawal

*Occurs when the caregiver no longer wants to stay in touch with friends, participate in activities once enjoyed.*

*Sign of depression*

*"I don't care anymore"*

Hopkins et al, 2017



**Emotional and Physical Triggers**  
Anxiety

*Worry on steroids and  
Fear of the future*

*Who will be there for my loved one, if I can't do this anymore?*



*Anxiety left alone, Despair*

DSM-5, 2013



**Emotional and Physical Triggers**  
Despair

*"I don't care anymore!"*

**Emotional and Physical Triggers**  
Review


*Denial*

*Anger*

*Withdrawal*

*Anxiety*


*Despair*



**Emotional and Physical Triggers**  
Discussion

*Of these first five triggers, which have you experienced  
and how have they changed your life?*

*What is your story?*




**Emotional and Physical Triggers**  
Exhaustion

*No more energy*

*"I do not have the energy to do anything anymore"*

*Exhaustion is always looking for the bed to crawl into,  
couch to curl up into, and the day to be over.*

*Exhaustion wants sleep, yet struggles to find it, even in  
bed*




**Emotional and Physical Triggers**  
Sleeplessness

*Hyper-vigilant to sounds, noise, cries of their loved  
one...*

*Startled by nightmares, stressful dreams, fears of the  
disease winning.*

*"I am alive and well, this seems so unfair to Jason"*  
*Menesia, (communication)*



**Emotional and Physical Triggers**  
Guilt

*Guilt cannot give enough, feels bad they feel that way,  
sorry for self, hopeless*

*Guilt drives in deep, sets up camp, feeds the belief  
system and violates the health of its attachment.*

*Hopkins et al, 2014*




**Emotional and Physical Triggers**  
Lack of Concentration

*Cannot focus anymore*

*Difficulty to complete complex tasks*

*Loosing their minds*


*Hopkins et al, 2014*



**Emotional and Physical Triggers**  
Health Problems

*Loss of weight, colds, flu, chronic backaches, headaches, high blood pressure, acne, diarrhea, skin issues, stomach aches, Crohns disease....*

*A body under stress is an oasis with illness waiting to invade*




**Losses Along the Journey**  
Session Two

*Loss of Identity*

*Loss of Partnership*


*Loss of Home*



**Losses Along the Journey**  
Session Two

*What have you lost?*

*What is your story?*




**Losses Along the Journey**  
Loss of Identity

*"Our sense of being derives from our identity with the world, and therefore the loss of identity carries with it the feeling of loss of being, of death"*

*Former identification no longer has a home... a spectator of our lives... invades not only the afflicted, but the entire family*

Washburn, 1996




**Losses Along the Journey**  
Loss of Partnership

*Outside activities disappear, friends distance themselves, purgatory*

*"In caring for a spouse, we learn that only the present is given to us and that is our choice how to react to it. It is the now that we live, and in the now that we can give."*


Rouche, 2000



**Losses Along the Journey**  
Loss of Home

*Home becomes redefined... roles are shaken... expectations renegotiated...*

*The caregiver wants to remain in a fairytale... the catastrophic illness forces us to leave behind the make believe*



**Losses Along the Journey**  
Loss of Home

*"... it is a patient heart that releases suffering, for it is not who we are when caregiving begins that defines our character and sets us free, but who we end up becoming."*

Roche, 2000

## Losses Along the Journey

### Anecdotal

*I'm different...*

*I am not sure who I am anymore...*

*These ambiguous losses can trigger complicated reactions with no rituals to guide them through the grief...*

Break!



## Compassion Fatigue

### Session Three

*...emotional residue of exposure to working with the suffering...*

*...not only the normal stress or dissatisfaction of work, but also with the emotional and personal feelings for the suffering.*


*"Compassion Fatigue is a state of tension and preoccupation with the individual or the cumulative trauma of clients, as manifested in one or more ways including re-experiencing the traumatic event, avoidance/numbing of reminders of the event, and persistent arousal."*

~ Charles R. Figley




### Compassion Fatigue is...

- Ongoing state of tension
- Preoccupation with a patient/family.
- Cumulative trauma.
- Re-experience of the trauma, avoiding/numbing the reminders of the event, and persistent arousal.
- Absorption of the trauma through the eyes and ears of your clients.



### Four Irrefutable Causes

- Empathy
- Repetition
- Transference
- Collision



### Empathy

Cause #1

- Definition:  
"An empathist is a person who maintains rapport with others through empathy."  
~ World Book Dictionary
- Another definition of empathy might be...  
"...quality or process of entering fully, through imagination, into another's feelings or motives."




### Empathy

*"As therapists, empathy is our major, greatest, and most reliable tool. Often it is our capacity for empathy that brings us to the helping professions in the first place..."*


~ Babette Rothchild, MSW






### Upsides of Empathy

- Empathy allows us to relate to our loved one.
- Empathy allows us to have a sense of what our loved one is feeling.
- Empathy allows perspective and understanding.
- Empathy allows insight and accurate hunches.



### Downfalls of Empathy

- We can care too much.
- We can confuse empathy with sympathy (pity).
- We can over-extend sympathy.
- Our gift can become a yoke to the emotional needs of both our loved one and our own needs.
- Loss of objectivity.



### A Great Read

"Empathy and Burnout in Nurses:  
Balancing Act." Kelly Bradham

[www.icsw.edu/\\_dissertations/bradham\\_2008.pdf](http://www.icsw.edu/_dissertations/bradham_2008.pdf)




### Empathy

Can you share where EMPATHY has  
been your ally and when it has been  
your enemy?

Examples?






## Repetition

### Cause #2

*"A debilitating weariness brought about by repetitive, empathic response to pain and suffering, compassion fatigue is a result of absorbing and internalizing the emotions of clients (loved ones)."*


~ Karl LaRowe



## Repetition

*"The difference for crisis responders (people helpers) is that with repeated interventions, these alterations can become solidified because the interventions confirm the validity of the changes in their beliefs. i.e. inherent to the hierarchy of human needs."*


~ Marlene A. Young/DOJ  
Community Crisis Response Team Training Manual



## Repetition

### Contributing Factors

- Constant re-exposure to sudden, random and arbitrary disaster.
- Exposure and re-exposure to the impossible.
- Lack of positive countervailing exposure to human good and world order.
- Lack of nurturing resources.



## Transference

### Cause #3

**Definition:**

*"...the inappropriate repetition in the present of a relationship that was important in a person's childhood..."*

~ Leonard H. Kapelovitz

## Transference

*"Hearing about past trauma can trigger haunting memories from a therapist's (chaplain, nurse, doctor) own past."*

~ Charles R. Figley  
Compassion Fatigue, 1995

John F Kennedy Jr. Funeral 1963



## Transference

### Contributing Factors

- A recent or similar trauma in the caregiver's life.
- Similarities between victim and caregiver.
- Physical or emotional fatigue.
- In one word.... CONNECTION

## Review of Causes

1. Empathy
2. Repetition
3. Transference

Any Questions?

## Collision Cause #4

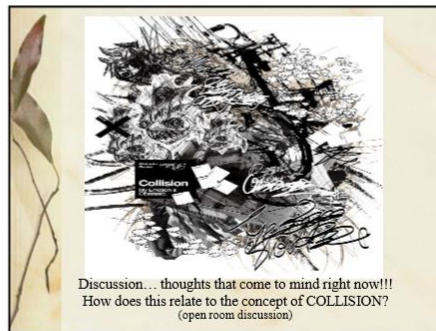


## Group Discussion

- How many instruments did you hear in this rhapsody?
- What did you hear beyond the music?

## 4. Collision

- You bring your past, present, and future dreams.
- You bring, recorded in you, your history, culture, drama, crisis, and celebration.
- You bring your vision for life, your dreams, your wishes, and ambition.
- You bring your talents, gifts, and abilities.
- You bring your concept of God and God's understanding of you.



## Collision

Yes it collides with your reality...


- Thus the friction...
- Thus the excitement...
- Thus the frustration...
- Thus the compassion fatigue....

## Review

1. Empathy
2. Repetition
3. Transference
4. Collision

Any Questions or Discussion?

## Break!



**Proven Action Steps**  
Session Four

"The combination of loss, prolonged stress, the physical demands of caregiving, and the biological vulnerabilities that come with age place you at risk for significant health problems as well as an earlier death."


Family Caregiver Alliance, 2003



**Proven Action Steps**  
Step One

***Be Good to Your Body***


The importance of good diet, exhaustive exercise, and a little pampering goes a long-way in dealing with the daily onslaught of stress and crisis the family faces



**Proven Action Steps**  
Step Two

***Lighten Your Load***


...through sharing it, through learning to talk about it, and through networking



**Proven Action Steps**  
Step Three

***Give the Pros a Chance***


...know when to raise your hand and ask for help  
*Pastor, Counselor, Doctor, Therapist*



**Proven Action Steps**  
Step Four

*Know Your Body and Emotions*


*Know one's priority of giving attention to personality and character....*



**Proven Action Steps**  
Step Five

*Re-write Your Inner Script*

Negative thinking is natural in the stressful life of a caregiver, but it is also a barrier to solving problems and reducing anxiety.




**Proven Action Steps**  
Step Five

*Re-write Your Inner Script*

Be Aware of:


- Generalizing
- Ignoring the Positive
- Jumping to Conclusions
- Labeling



**Proven Action Steps**  
Step Six

*Tell Yourself the Truth*


explore and never accept ambiguity  
research and hope for discovery will fall short of desired goals  
know your own limitations and to honor them



**Proven Action Steps**  
Step Seven

*Take a Vacation*

*The "ten minute" vacation*  
*Invest in music*  
*Taking weekly walks through nature, art, and theater*



**Proven Action Steps**  
Step Eight

*Invite Spirituality*

Through reading Scripture, listening to uplifting and encouraging music, prayer, and meditation, and through both personal and corporate worship, the soul and spirit is enriched and blessed.



**Proven Action Steps**  
Discussion

- What areas do you resonate with?
- What areas do you think you could add to your workweek or to your home life?



Thank you!

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Christopher Buck is married to Michele, 45 years, and has two adult children, Jennie and Jacob. Between them they have eight grandchildren and all reside in Salem, Oregon. Christopher is a Marriage Family Therapist at The Counseling Center, in Albany, Oregon.